# In the Constitutional Court of Colombia

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# BRIEF OF GERARD QUINN, UNITED NATIONS SPECIAL RAPPORTEUR ON THE RIGHTS OF PERSONS WITH DISABILITIES AND CLAUDIA MAHLER, UNITED NATIONS INDEPENDENT EXPERT ON THE ENJOYMENT OF ALL HUMAN RIGHTS BY OLDER PERSONS AS AMICI CURIAE IN SUPPORT OF PETITIONERS

**April 25, 2022**

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## I. Statement of Interest of Amici Curiae

Mr. Gerard Quinn, United Nations Special Rapporteur on the rights of persons with disabilities, and Ms. Claudia Mahler, United Nations Independent Expert on the enjoyment of all human rights by older persons, (the "Amici Curiae") are independent experts appointed by the United Nations Human Rights Council with mandates established pursuant to Human Rights Council resolutions 26/20 of 27 June 2014 and 24/20 of 27 September 2013, respectively, to "conduct, facilitate and support the provision of advisory services … in support of national efforts for the effective realization of the rights of persons with disabilities" and "to work in cooperation with States in order to foster the implementation of measures that contribute to the promotion and protection of the rights of older persons".

Persons with disabilities and older persons are especially at risk in health care decision-making, including in the context of COVID-19, in the face of medical triage protocols promulgated non-transparently, without stakeholder inputs, invoking criteria based on disability and age and long-term survivability, contrary to the principles and standards set out in international human rights law.

The Amici Curiae share a strong interest in the outcome of this case for three central reasons:

Firstly, their individual and combined experiences advocating for the rights of persons with disabilities and older persons,

Secondly, their more specific interest in preventing discrimination in health care decision making against both cohorts, and

Thirdly, their concern regarding the exclusion of these groups from meaningful participation in decisions affecting health policies and processes that affect their interests.

In the performance of his or her mandate as Special Rapporteur or Independent Expert, the Amici Curiae are accorded certain privileges and immunities as experts on mission for the United Nations pursuant to the Convention on the Privileges and Immunities of the United Nations, adopted by the United Nations General Assembly on 13 February 1946.

The present submission is provided on a voluntary basis for the consideration of the Colombian Constitutional Court without prejudice to, and should not be considered as a waiver, express or implied, of the privileges and immunities of the United Nations, its officials and experts on mission, pursuant to the 1946 Convention on the Privileges and Immunities of the United Nations.

In full accordance with their independence afforded to the respective mandates of the Amici Curiae, authorization for the positions and views expressed herein was neither sought nor given by the United Nations, including the Human Rights Council and the Office of the High Commissioner for Human Rights, or any of the officials associated with those bodies.

The current Special Rapporteur on the rights of persons with disabilities, Mr. Gerard Quinn, was appointed by the Human Rights Council at its 45th session, in October 2020. Mr. Quinn holds

two research chairs at the Raoul Wallenberg Institute on Human Rights in the University of Lund (Sweden) and Leeds University (UK). A graduate of Harvard Law School, the King's Inns (Dublin) and the National University of Ireland, he formerly held a chair at the National University of Ireland where he founded and directed the Centre on Disability Law & Policy. In Ireland, he served as a member of the Commission on the Status of People with Disabilities (1992-1996) which was composed of a majority of persons with disabilities. He served two terms on Irelands' Human Rights Commission. At the invitation of the President of Ireland, he served on the Council of State (Ireland) from January 2012-2018. Mr. Quinn was the lead 'focal point' for the global network of National Human Rights Institutions (NHRIs) during much of the negotiation of the UN Convention on the Rights of Persons with Disabilities and was head of delegation for Rehabilitation International during the UN Working Group (2004). He has served as First Vice-President of the European Committee on Social Rights (a human rights monitoring body on economic and social rights in the Council of Europe) where he helped develop its jurisprudence on the rights of persons with disabilities and older persons.

The current Independent Expert on the enjoyment of all human rights by older persons, Ms. Claudia Mahler, was appointed by the Human Rights Council in May 2020. She has been working for the German Institute for Human Rights as a senior researcher in the field of economic, social and cultural rights since 2010. She also served as a visiting professor at the Alice Salomon Hochschule in Berlin. From 2001 to 2009, Ms. Mahler conducted research at the Human Rights Centre of the University of Potsdam where her main fields were in human rights education, minority rights and the law of asylum. In 2000, she was appointed Vice President of the Human Rights Commission for Tyrol and Vorarlberg. She has also worked as a lecturer in the field of human rights law and as a consultant to the Office of the High Commissioner for Human Rights (OHCHR) in Geneva. From 1997-2001, she held the position of an assistant at the Leopold-Franzens-University Innsbruck, Austria in the field of Criminal Law and Criminal Procedures and received her doctoral degree in 2000.

## II. Introduction and Summary of Arguments

Measures adopted by the State must be effectively necessary to combat the public health crisis posed by the COVID-19 pandemic, while also being reasonable and proportionate to their legitimate purpose. Crisis standards of care, including medical triage protocols, must comply with international human rights standards, especially the principles of equality and non-discrimination. Further, procedural bioethical obligations must also be respected in the development of such measures.

First, the right to equality and non-discrimination is breached where COVID-19 triage protocols would result in denials of life-saving treatment to persons with disabilities and older persons, including those explicitly or indirectly premised on disability, age, presumed life expectancy or remaining "life years" or due to presumptions as to quality of life.

Secondly, such measures further offend the right to life, the right to the highest attainable standard of health and the principle of protection for persons with disabilities and older persons during situations of risk.

Last, where such protocols are promulgated non-transparently in the absence of stakeholder input, they also stand as contrary to the principles and standards set out in international human rights law, including the Universal Declaration of Human Rights (UDHR), the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the nearly universally ratified Convention on the Rights of Persons with Disabilities (CRPD).[1]

## III. General Obligations Arising from International Human Rights Law

The general obligations arising from international human rights law, including the obligations set out in the UDHR, the ICCPR, the ICESCR and the CRPD, most pertinent to assessing the alignment of crisis standards of care and medical triage protocols with human rights standards include:

1) the obligation not to discriminate, directly or indirectly, on the basis of disability or age;

2) flowing from non-discrimination is the obligation not to design medical protocols based on spurious and speculative quality of life assessments that track long term survivability without an individualized, immediate survivability calculus; and

3) the obligation not to perpetuate disability-based and age-based bias and associated harmful stereotyping contrary to a State's duty to respect, protect and fulfill the human rights of persons with disabilities and older persons, including non-discrimination.

### A. Crisis standards of care measures adopted by a State during global pandemics must comply with principles of equality and non-discrimination.

Crisis standards of care, such as medical triage protocols, typically place treatment priority on those deemed more likely to survive hospitalization. Such protocols, adopted in the context of the COVID-19 pandemic, are sometimes necessary during crisis situations involving an extreme scarcity of resources.

[1] Universal Declaration of Human Rights (UDHR), United Nations General Assembly (1948); International Covenant on Civil and Political Rights (ICCPR), United Nations Treaty Series, vol. 999, UN General Assembly (December 16, 1966); International Covenant on Economic, Social and Cultural Rights ICESCR), art. 2, (December 16, 1966), United Nations Treaty Series, vol. 993, p. 3; Convention on the Rights of Persons with Disabilities (CRPD), UN Doc. A/RES/61/106 (December 13, 2006).

These measures may not, as a matter of international human rights law, discriminate on the basis of disability, age, gender, race, ethnicity, and other attributes.[2] Nor may such medical triage protocols give lower priority to individuals seeking treatment based on speculation as to a patient's long-term survival odds, speculation as to quality of life or based solely on a patient's age or particular disability, in instances where such individuals stand to benefit from treatment and survive as a result of such treatment.[3]

### i. Crisis standards of care may not discriminate on the basis of disability.

International human rights law recognizes the dignity of all human beings and affirms the equal worth of all lives.[4] Rationing protocols developed by healthcare providers in response to COVID-19 may not inflict discrimination "on the basis of" disability, pursuant to the prohibition against discrimination in Article 5 of the CRPD.[5] Thus, disability may not be used as an explicit factor to deny treatment in a crisis care standard.[6]

In addition, disability may not be used to effectuate indirect discrimination as prescribed by Article 2 of the CRPD. The CRPD prohibition against discrimination on the basis of disability as includes "any distinction, exclusion or restriction on the basis of disability which has the purpose *or effect* of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms…"[7]

Crisis care standards that fail to adhere to the benchmark of *survival in the immediate term* have been found to offend disability rights principles, including non-discrimination.[8] Such standards

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[2] CRPD, *supra* note 1 at art. 5. *See also* UN Human Rights Council, *Report of the Independent Expert on the enjoyment of all human rights by older persons, Claudia Mahler, Impact of the coronavirus disease (COVID-19) on the enjoyment of all human rights by older persons,* A/75/205, (July 21, 2020), https://digitallibrary.un.org/record/3879146; United Nations Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, *Joint Statement: Persons with Disabilities and COVID-19* (April 1, 2020), https://www.ohchr.org/en/statements/2020/04/joint-statement-persons-disabilities-and-covid-19-chair-united-nations-committee?LangID=E&NewsID=25765.

[3] UN Human Rights Council, *supra* note 2, para. 16 ("The pandemic has shown that, in practice, hospitals introduce a triage approach in response to insufficient resources. Triage procedures needed in such situations must be in line with human rights tenets. Withholding or refusing the provision of medical treatment on the basis of an age limit or social worth is implicitly prohibited under international human rights law.") *Id.*

[4] United Nations, *Charter of the United Nations, Preamble,* 24 October 1945, 1 UNTS XVI, available at: https://www.refworld.org/docid/3ae6b3930.html [accessed 16 April 2022] (reaffirming "faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small).

5 CRPD *supra* note 1 at art. 5. *See also The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Ilias Bantekas, Michael Ashley Stein & Dimitris Anastasiou eds.) Oxford University Press, (November 2018) https://opil.ouplaw.com/view/10.1093/law/9780198810667.001.0001/law-9780198810667.

[6] *Id*. at art. 2 (prohibiting "*all* discrimination on the basis of disability.") [emphasis added]. *Id.*

[7] *Id*. at art. 2.

[8] *See COVID-19 Medical Rationing,* Center for Public Representation, https://www.centerforpublicrep.org/covid-19-medical-rationing/
Successful complaints resulting in the withdrawal or amendment of crisis standards of care have been filed against numerous US States in the context of COVID-19. The Center for Public Representation maintains an updated website compiling these complaints.

should likewise, in addition to directing decision-making to survival in the immediate term, reflect safeguards to ward off disability or other bias.

The application of these principles is usefully illustrated by an American case. At the outset of the COVID-19 pandemic, the State of Alabama in the United States (US) maintained crisis care standards that allowed for the denial of ventilator services to individuals based on the presence of intellectual disabilities, including "profound mental retardation" and "moderate to severe dementia." An intervention by the Office for Civil Rights (OCR) at the United States Department of Health and Human Services (HHS) led to a reform of the protocol.[9] They offended the requirement of non-discrimination on the basis of disability given that they reflected treatment decisions *because* of an individual's status as a person with disability. Such decision-making standards are, on that basis, contrary to the explicit prohibition against disability discrimination reflected in the CRPD.[10] The Alabama case thus supports illustrates the application in practice of the proposition that crisis care standard protocols must give full effect to non-discrimination policies. Likewise, they must incorporate the prohibition against disparate impact and integrate into their framework reasonable accommodation such that individuals with disabilities have the opportunity to benefit from medical treatment.[11]

### ii. Crisis standards of care may not discriminate on the basis of old age.

The withholding of medical treatment or the refusal to provide treatment on the basis of age or an age limit which dictates when someone may receive care is, unless justified by extraordinary circumstances, prohibited under international human rights law.[12] Article 25 of the UDHR further ensures the right to access medical care and health services and to security explicitly in old age.

States are therefore obliged under human rights law to "ensure that medical services, which are crucial for the continued healthy living of older persons, are available on a non-discriminatory basis, even during lockdowns."[13] Protocols adopted by numerous States in the midst of the pandemic, such as crisis standards of care and medical triage protocols, may not invoke old age

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[9] U.S. Department of Health and Human Services Press Office, *OCR Reaches Early Case Resolution with Alabama After It Removes Discriminatory Ventilator Triaging Guidelines*, U.S. DEP'T HEALTH & HUM. SERVS. (Apr. 8, 2020), https://public3.pagefreezer.com/content/HHS.gov/31-12-2020T08:51/https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html#:~:text=Today%2C%20the%20Office%20for%20Civil,basis%20of%20disability%20and%20age; Center for Public Representation, *COVID-19 Medical Rationing*, https://www.centerforpublicrep.org/covid-19-medicalrationing/. Numerous complaints have been filed against US States on similar grounds. These are available at a database maintained by the Center for Public Representation.

[10] CRPD, *supra* note 1 at art. 5.

[11] *See* U.S. Department of Health and Human Services, Office for Civil Rights, *Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)*, p. 2, (Mar. 28, 2020), https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf. Guidance from the U.S. Department of Health and Human Services emphasizes this point in its COVID19 circular: "Being mindful of all segments of the community and taking reasonable steps to provide an equal opportunity to benefit from emergency response efforts, including making reasonable accommodations will help ensure that the emergency response is successful and minimizes stigmatization."

[12] UN Human Rights Council, *supra* note 2.

[13] *Id.*

as a basis for disqualification from treatment or give older persons lower priority for treatment solely on that basis.[14]

The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health emphasized the right of older persons to equality and non-discrimination in accessing health care, noting that

> under the right-to-health framework, health facilities, goods and services should be made available … in sufficient quantity.[15]

The Special Rapporteur further noted that, very often:

> older persons are affected by selective unavailability because of rationing of medical care, i.e. allocation and prioritization of health resources, which often results in de-prioritizing older persons for health treatment.[16]

Under Article 2 of the ICESCR, States Parties undertake to achieve the rights in the Covenant, to the maximum of their available resources, without discrimination of any kind.[17] This applies in respect of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, guaranteed in Article 12. Ableist and ageist practices with regard to the enjoyment of the right to health are therefore prohibited. Further, States Parties, as duty bearers,

> must ensure that public health policies have no discriminatory or ageist policies against older persons.[18]

In its General Comment No. 14 (2000) on the right to the highest attainable standard of health, the United Nations Committee on Economic, Social and Cultural Rights (CESCR) set out the conditions under which States Parties must carry out their obligations with respect to the right to health. This includes ensuring accessibility in four dimensions:

- non-discrimination,
- physical accessibility,
- economic accessibility and

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[14] *See* Office of the United Nations High Commissioner for Human Rights, "*'Unacceptable' – United Nations expert urges better protection of older persons facing the highest risk of the COVID-19 pandemic*", (27 March, 2020) https://www.un.org/development/desa/ageing/news/2020/03/covid-19/; United Nations Sustainable Development Group, *Policy brief: the impact of COVID-19 on older persons*, United Nations (May, 2020) https://unsdg.un.org/resources/policy-brief-impact-covid-19-older-persons.

[15] UN Human Rights Council, *Report of the Special Rapporteur on the right to the highest attainable standard of health*, A/HRC/18/37, para. 25. United Nations General Assembly (March 16, 2011), https://documents-dds-ny.un.org/doc/UNDOC/GEN/G11/118/42/PDF/G1111842.pdf?OpenElement.

[16] UN Human Rights Council, *supra* note 15; *See also* UN Human Rights Council, *supra* note 2; Elizabeth Lee Daugherty Biddison et al., *Too many patients – a framework to guide statewide allocation of scarce mechanical ventilation during disasters*, 155 CONTEMPORARY REVIEWS IN CRITICAL CARE MEDICINE (April 2019).

[17] See ICESCR, *supra* note 1 at art. 2.

[18] UN Human Rights Council, *supra* note 2.

- information accessibility.[19]

Further, the Committee underscored that the "right to treatment includes the creation of a system of urgent medical care in cases of … epidemics … and the provision of disaster relief and humanitarian assistance."[20]

In addition to international instruments, at the regional level, the Inter-American Convention on Protecting the Human Rights of Older Persons guarantees in Article 11 the right to give free and informed consent on health matters.[21] Therefore "information provided is appropriate, clear and timely, available on a non-discriminatory basis in an accessible and easily understood form, and commensurate with the older person's cultural identity, level of education, and communication needs."[22]

### iii. Crisis standards of care may not be discriminatory in their impact.

Even where medical triage protocols do not have evident or explicit discriminatory intent, they may nonetheless be discriminatory in their impact on persons with disabilities and older persons and thereby fall afoul of the prohibition against discrimination on the basis of age, disability or other status.[23]

Consistent with principles of equality and non-discrimination firmly embedded in international human rights law,[24] governments may not use COVID-19 measures in a manner which disproportionately impacts or restricts the rights of persons based on their disability, age or other factors.

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[19] Economic and Social Council, *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, E/C.12/2000/4, UN Committee on Economic, Social and Cultural Rights (August 11, 2000) [accessed 17 April 2022] https://digitallibrary.un.org/record/425041.

[20] *Id.*

[21] *See* Inter-American Convention on Protecting the Human Rights of Older Persons, art. 11, Organization of American States General Assembly (January 11, 2017), https://www.oas.org/en/sla/dil/inter_american_treaties_a-70_human_rights_older_persons.asp.

[22] *Id.*

[23] *See* CRPD, *supra* note 1 at arts. 2, 5. *See also* Deborah Hellman & Kate Nicholson, Rationing and Disability in a State of Crisis, Va. Pub. L. & Legal Theory Research Paper No. 2020–33 (October 29, 2021), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3570088 (Explaining why medical rationing—even if not based on explicit disability classifications—is prohibited when it has a forbidden disparate impact on individuals with disabilities).

[24] *See* ICCPR, *supra* note 1 at art. 2; ICESCR, *supra* note 1 at art. 2; United Nations Treaty Series, Convention on the Rights of the Child vol. 1577, UN General Assembly (November 20, 1989); United Nations Treaty Series, Convention on the Elimination of All Forms of Discrimination Against Women vol. 1249, UN General Assembly (December 18, 1979); United Nations Treaty Series, International Convention on the Elimination of All Forms of Racial Discrimination, vol. 660, UN General Assembly (December 21, 1965); Universal Declaration of Human Rights, G.A. Res. 217 (III) A, art. 5, U.N. Doc. A/RES/217(III) (December 10, 1948). See also Organization of American States, American Convention on Human Rights, art. 5, O.A.S.T.S. No. 36, 1144 U.N.T.S. 123 (November. 22, 1969); Organization of American States, Inter-American Convention to Prevent and Punish Torture, art. 2, O.A.S.T.S. No. 67, 25 I.L.M. 519 (September 12, 1985); African Charter on Human and Peoples' Rights, art. 5 1520 U.N.T.S. 217 (June 27, 1981).

States must also be mindful of intersectional discrimination, where individuals have more than one status associated with bias in medicine, and wherever persons with disabilities face discrimination that is layered, compounded, and distinct within the States society.[25]

### B. Crisis standards of care must be necessary, reasonable and proportionate to their legitimate purpose.

Measures adopted and applied during the pandemic must be effectively necessary to combat the public health crisis posed by the pandemic.[26]

Accordingly, they must be developed and implemented to address a situation where, as a result of serious constraints on medical resources like those occurring during a pandemic, such measures are necessary. Thus, crisis standards of care protocols must be necessary to facilitate decision-making in public health contexts. Further, crisis standards of care must also be reasonable and proportionate to their legitimate purpose.[27]

A pandemic—or any other emergency—may not be invoked to justify the introduction of protocols and policies limiting or withdrawing non-derogable human rights, including the right to life. Such protocols and policies may not disproportionately impact a particular segment of the population where decisions are made under a protocol triggered solely by a protected status (e.g., disability, age). Illustratively, these concepts are well-reflected in the US State of California Department of Public Health, *California SARS-CoV-2 Pandemic Crisis Care Guidelines*, which provides that:

> Healthcare decisions, including allocation of scarce resources, cannot be based on age, race, disability (including weight-related disabilities and chronic medical conditions), gender, sexual orientation, gender identity, ethnicity (including national origin and language spoken), ability to pay, weight/size,

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[25] Center for Public Representation, Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination against COVID 19 Patients (February 11, 2021) https://www.centerforpublicrep.org/wp-content/uploads/FINAL-Intersectional-Guide-Crisis-Care-PDF.pdf.

[26] UN Human Rights Council, *Final report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Pūras*, para. 33, A/75/163 (July 16, 2020) https://digitallibrary.un.org/record/3878993?ln=en. *See also* UN Commission on Human Rights, *The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights*, E/CN.4/1985/4 (September 28, 1984) [accessed 16 April 2022] https://www.icj.org/wp-content/uploads/1984/07/Siracusa-principles-ICCPR-legal-submission-1985-eng.pdf. Further, the Siracusa Principles provide that States Parties to the present Covenant recognize that, in the enjoyment of those rights provided by the State in conformity with the present Covenant, the State may subject such rights only to such limitations as are determined by law only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society. Such limitations on restrictions on rights are also set out in the Siracusa Principles and provide protections for individuals from discriminatory and unnecessary restrictions and require more concrete integration into national and local public health laws and policies in order to be effective.

[27] UN Human Rights Council, *supra* note 26 at para. 15. (¨Stressing that "[i]t is also essential that the measures adopted by States to combat this pandemic are in agreement with the Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights (1984) and are therefore time-limited, reasonable, proportionate, non-discriminatory and grounded in law to ensure protection of all human rights, recognizing that human rights are indivisible and inalienable…")

socioeconomic status, insurance status, perceived self-worth, perceived quality of life, immigration status, incarceration status, homelessness, or past or future use of resources.[28]

### C. Disability and age-based long-term survival or remaining life years assessments are arbitrary and rooted in arbitrary and erroneous judgments about the life prospects of persons with disabilities and older persons and are prohibited under international human rights law.

The determination by medical professionals and others that old age or disability necessarily limits the quality of a person's life reflects a dubious, highly subjective exercise which very often has no bearing at all on the view of persons with disabilities or older persons themselves, as is amply documented in research.[29] Such assessments are arbitrary and contrary to international human rights law principles of non-discrimination and freedom of live in dignity.

Assessments as to long-term survivability or remaining life years are exposed for their erroneous and wrong-headed judgments in studies showing that physicians and medical professionals are unable to predict with any accuracy how an individual's disability will impact a person's life expectancy or determine reliably the long-term survivability of an individual with a particular disability or a particular health condition.[30] As such, crisis standard of care protocols premised on a doctor's view as to long-term survivability are problematic. Further, they constitute an inappropriate and illegitimate exercise of "medical autonomy."

Standards of care that are premised on presumed life expectancy or remaining life years are discriminatory on their face. With regard to age, physicians and medical professionals tend to assume that a person in later life is at the end of the life course.[31] It is not possible to determine how long a person may live in the long term after receiving the necessary medical treatment, especially since globally, life expectancy continues to increase over time. Between 2000 and

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[28] California Department of Public Health, *California SARS-CoV-2 Pandemic Crisis Care Guidelines* (June 2020) https://www.strosehospital.org/images/documents/CA_COVID-19_Crisis_Care_Guidelines.pdf.

[29] Samuel R. Bagenstos, *May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing*, 130 YALE LAW JOURNAL FORUM (August 19, 2020) ("A massive body of research has demonstrated that people who acquire a range of disabilities typically do not experience much or any permanent reduction in the enjoyment of life."). Elizabeth F. Emens, *Framing Disability*, (October 15, 2012) U. ILL. L. REV. 1383, 1386 ("From the outside, disability commonly looks like an unhappy place created by an individual medical problem for which the law sometimes provides special benefits to that individual. From the inside, disability often looks like a mundane feature of a no-less-happy life, rendered inconvenient or disabling largely by interactions with the surrounding environment, which legal accommodations alter in ways that sometimes provide benefits to many.").

[30] California Department of Public Health, *supra* note 28. *See also* Kevin M. Leung, Wilma M. Hopman, & Jun Kawakami, 6 Can. Urol. Assoc. J. (5), 367-73 (October, 2012), http://dx.doi.org/10.5489/cuaj (Concluding that "physicians do poorly at predicting life expectancy and tend to underestimate how long patients have left to live").

[31] M.G. Clarke, P. Ewings, T. Hanna, L. Dunn, T. Girling, T., & A.L. Widdison, *How accurate are doctors, nurses and medical students at predicting life expectancy?*, 20 European Journal of Internal Medicine (6), 640-644 (August 06, 2009) https://www.ejinme.com/article/S0953-6205(09)00125-3/fulltext. (Concluding that doctors, nurses and medical students were "inconsistent, inaccurate and imprecise" in predicting life expectancy "with a tendency toward underestimation." This may lead to patients being managed inappropriately. There is a need for improved training and objective outcome prediction models).

2019, for example, life expectancy increased by 6 years.[32] The key decisional point for triage determination in the context of scarce resources is survival in the immediate term if treated. Basing the decision on the assumption based on quality of life that an older person has fewer remaining years to live than a younger one is arbitrary and illegitimate.

Human rights law prohibits the invocation of disability as the basis for denying life-saving treatments that a person requires and may benefit from receiving.[33] The principles set out in the CRPD likewise supports a clear, objective basis for determining that a person is likely to die in the immediate term as the result of a pre-existing disability and such determinations must be made within a procedural framework that protects against disability or other bias.[34]

Permissible procedures to provide life-saving treatment in triage situations may include the consideration of a range of factors that are consistent with disability discrimination law as well as disability rights principles. The application of such criteria aligned with international human rights principles is usefully reflected in practice. In the response by US Secretary of Health and Human Services Louis Sullivan to the State of Oregon's Secretary of State's plan to form a State level disability and health law policy, a system may consider:

> [A] wide range of factors" that are consistent with disability law and policy. Such factors may include, among others, "the cost of medical procedures, the length of hospital stays, prevention of death, and prevention of contagious diseases" and indeed "any content neutral factor that does not take disability into account or that does not have a particular exclusionary effect on persons with disabilities. [35]

Consistent with non-discrimination on the basis of disability, Secretary Sullivan proposed that such factors may not result in the denial of lifesaving treatment simply because on the basis of a patient's pre-existing disability or age.[36]

In the light of the foregoing and consistent with international human rights law protecting persons with disabilities and older persons from arbitrariness and discrimination in decision-making in the context of realizing their human rights and fundamental freedoms, States may not premise disability and aged-based assessments on long-term survivability or conjecture as to remaining life years.

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32 WHO, *GHE: Life expectancy and healthy life expectancy*, available at https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/ghe-life-expectancy-and-healthy-life-expectancy

[33] CRPD, *supra* note 1 at art. 25.

[34] *Id.* at art. 5, 25. *See also* Bagenstos, *supra* note 29.

[35] *Secretary Sullivan. ADA Analyses of the Oregon Health Care Plan*, *infra* note 54 at pg. 411. These factors were in fact used the illustrate the type of considerations deemed appropriate under American federal disability law in the context of an analysis of the Oregon Health Care Plan.

[36] *See* Andrew H. Smith & John Rother, *Older Americans and the Rationing of Health Care*, 140 U. PA. L. REV. 1847, 1853 (1992) (analyzing the problem with age-based rationing because "some would justify the withholding of expensive medical services to older persons on the basis of the decreased productivity of the elderly.").

### D. States fail to respect, protect and fulfill human rights if they support or acquiesce in policies that reinforce harmful stereotypes about persons with disabilities.

As indicated by the World Health Organization,

> [t]hose responsible for infectious disease outbreak response should ensure that all individuals are treated fairly and equitably regardless of their social status or perceived 'worth' to society. They should also take measures to prevent stigmatization and social violence.[37]

The United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee), in its reporting guidelines, calls on States to report on "the measures they have taken to raise awareness of persons with disabilities, to foster respect for their rights and dignity, their capabilities and contributions, and to combat stereotypes, and prejudices against them."[38]

Quality of life assessments that are rooted in ableist and ageist assumptions are not valid applications of medical autonomy in medical triage protocols. Rather, they reinforce stigma and stereotyping on the basis of disability that the CRPD Committee sets out to combat.[39]

Evaluating an individual's quality of life informs a vast range of medical decision making and evaluative processes.[40] Scholars working from a disability studies and disability rights orientation emphasize that policies grounded in quality-of-life assessments too often have the effect of reinforcing the historical stigmatization of a persons with disabilities.[41]

Research supports the conclusion that health care providers hold perceptions about quality of life for persons with disabilities that are distinctly at odds with the perceptions of individuals with

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[37] World Health Organization, *Guidance for Managing Ethical Issues in Infectious Disease Outbreaks* (2016), p. 18 https://apps.who.int/iris/bitstream/handle/10665/250580/9789241549837-eng.pdf?sequence=1&isAllowed=y.

[38] CRPD Committee, *Reporting Guidelines on treaty-specific document to be submitted by States parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities*, *Article 8*, CRPD/C/2/3, United Nations Digital Library (November 18, 2009) https://digitallibrary.un.org/record/672005?ln=en.

[39] CRPD, *supra* note 1 at art. 8. CRPD Committee, *Concluding Observations on the combined second and third report of Hungary*, para. 50, CRPD/C/HUN/CO/2-3 (March 25, 2022) ("Attitudinal barriers and limited knowledge of the rights and requirements of persons with disabilities among health care professionals.)

[40] Robert L. Schalock, Gordon S. Bonham, & Christine B. Marchand, *Consumer based quality of life assessment: A path model of perceived satisfaction.* 23 EVALUATION AND PROGRAM PLANNING 77—88 (2000). Robert L. Schalock et. al., *Quality of Life Model Development and Use in the Field of Intellectual Disability*, Social Indicators Research Series, Vol. 41 (August 05, 2010) [accessed Apr 13 2022] .https://www.researchgate.net/publication/225939030_Quality_of_Life_Model_Development_and_Use_in_the_Field_of_Intellectual_Disability.

[41] Peter A. Ubel, George Loewenstein, & Christopher Jepson, *Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public*, 12 QUALITY OF LIFE RESEARCH 599–607 (2003); , *Quality-Adjusted Life Years and the Devaluation of Life with Disability*, National Council on Disability (November 6, 2019), https://ncd.gov/sites/default /files/NCD_Quality_Adjusted_Life_Report_508.pdf; Jerome Bickenbach, *Disability and Health Care Rationing*, STANFORD ENCYCLOPEDIA OF PHIL. (Edward N. Zalta ed., Spring 2016) https://plato.stanford.edu/archives/spr2016/entries/disability-care-rationing (summarizing ethical studies on the problem of relying on quality-adjusted life years in respect of persons with disabilities).

disabilities themselves.[42] The CRPD Committee summed up concerns surrounding the devaluation of the lives of persons with disabilities and attendant assumptions about quality of life as follows:

> As research has shown, the lower estimation of the quality of life of persons with disabilities by external observers, including many bioethicists, are caused by unconscious biases towards persons with disabilities.[43]

Disability-biased triage protocols raise concerns expressed by the disability community that such protocols pose risks for the kind of stereotyping that the CRPD aims to combat. This concern forms part of the basis for reforms undertaken in respect of crisis standards of care adopted in various jurisdiction in response to COVID-19. Illustratively, guidance provided by the US Department of Health and Human Services in the context of adhering to disability rights law in medical treatment decisions emphasizes, in pertinent part:

> [P]ersons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.[44]

## IV. Specific Obligations

Crisis standards of care, including medical triage protocols, shall be based on bioethical standards that must be consistent with and refrain from violating human rights obligations, including 1) the right to life; 2) the right to the highest attainable standard of health; and 3) obligations to protect specific groups during situations of risk.

These rights and obligations are owed equally to persons with disabilities, older persons, and other groups subject to historic and contemporaneous discrimination and disadvantage.

### E. Persons with disabilities and older persons enjoy the right to life on an equal basis with others.

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[42] *See, e.g.*, Carol J. Gill, *Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia*, 6 PSYCHOL., PUB. POL'Y & L. 526, 530 (2000); Tom Shakespeare, Lisa I. Iezzoni & Nora E. Groce, *Disability and the Training of Health Professionals*, 374 LANCET 1815 (2009); *Medical Futility and Disability Bias*, 29 NAT'L COUNCIL ON DISABILITY (Nov. 20, 2019), https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf [https://perma.cc/MY63-33FZ] ("Several studies have demonstrated that health care providers' opinions about the quality of life of a person with a disability significantly differ from the actual experiences of those people. For example, one study found that only 17 percent of providers anticipated an average or better quality of life after a spinal cord injury (SCI) compared with 86 percent of the actual SCI comparison group. The same study found that only 18 percent of emergency care providers imagined that they would be glad to be alive after experiencing a spinal cord injury, in contrast to the 92 percent of actual SCI survivors.") (footnotes omitted).

[43] *See* Ron Amundson, *Quality of Life, Disability, and Hedonic Psychology*, 40 JOURNAL FOR THE THEORY OF SOCIAL BEHAVIOUR (November 2010).

[44] *See* U.S. Department of Health and Human Services, *supra* note 11 at p. 2.

Persons with disabilities and older persons enjoy the right to life under international human rights law. Article 6 (1) of the ICCPR recognizes and protects the right to life for all persons, imposing the obligation and duty on States to protect human lives against risks, including health risks, that may result in the deprivation of life. The Human Rights Committee, in its General Comment No. 36, underscored that the right to life and equal dignity applies to all people and recognized that the right to life applies equally and without discrimination on the basis of age or disability.[45]

Article 10 of the CRPD recognizes and protects the right to life of persons with disabilities on an equal basis with others.[46] The CRPD reaffirms that every human being has the inherent right to life and underscores the concern that the lives of persons with disabilities must be recognized as having value equal to those of any other human being.[47] To that end, Article 10 calls on States to take

> all necessary measures to ensure the effective enjoyment of the right to life by persons with disabilities on an equal basis with others.[48]

The Inter-American Convention on Protecting the Human Rights of Older Persons further affirms in article 6 that all measures necessary must be adopted by States to "ensure older persons' effective enjoyment of the right of life and the right to live with dignity in old age until the end of their life on an equal basis with other segments of the population."[49]

These normative instruments generate bioethical standards on the right to life applicable to persons with disabilities and older persons. It entails a positive duty to protect the lives of persons with disabilities and older persons from all acts and omissions that are intended or may be expected to cause their unnatural or premature death, as well as ensuring respect, dignity and quality of life to persons with disabilities on an equal basis with others in all spheres of society

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[45] UN Human Rights Committee, *General comment no. 36, Article 6 (Right to Life), para. 18, 61*, CCPR/C/GC/35, United Nations Digital Library (September 3, 2019) https://digitallibrary.un.org/record/3884724?ln=en. (The right to life must be respected and ensured without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, or any other status, including caste, ethnicity, membership of an indigenous group, sexual orientation or gender identity, disability, socioeconomic status, albinism and age. Legal protections for the right to life must apply equally to all individuals and provide them with effective guarantees against all forms of discrimination, including multiple and intersectional forms of discrimination.); *See also* United Nations Sustainable Development, *supra* note 14 at page 6. (The Secretary General noted in a brief on the impact of COVID 19 on older persons that "[o]lder persons have the right to die with dignity and without pain.") https://unsdg.un.org/sites/default/files/2020-05/Policy-Brief-The-Impact-of-COVID-19-on-Older-Persons.pdf

[46] CRPD, *supra* note 1 at art. 10.

[47] *Id*. at Preamble & art. 10. *See also The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Ilias Bantekas, Michael Ashley Stein & Dimitris Anastasiou eds.) Oxford University Press, (November 2018) https://opil.ouplaw.com/view/10.1093/law/9780198810667.001.0001/law-9780198810667.

[48] *Id*. at art. 10.

[49] *See* Inter-American Convention on Protecting the Human Rights of Older Persons, Organization of American States General Assembly (January 11, 2017), https://www.oas.org/en/sla/dil/inter_american_treaties_a-70_human_rights_older_persons.asp.

and at all stages of life. As emphasized by the Human Rights Committee, "[t]he duty to protect the right to life by law also includes an obligation for States parties to adopt any appropriate laws or other measures in order to protect life from all reasonably foreseeable threats, including from threats emanating from private persons and entities."[50]

Recognition that the lives of persons with disabilities and older persons have been put at risk because of biased medical decision-making and perceived low quality of life is well-documented.[51] The recourse of triage policies does not allow under international human rights law criteria of selection or "rationalization" of human lives, based on a person's disability or age.[52] Disability and old age may not be used as a justification for termination of life or lifesaving treatment nor for the imposition of medical triage based on inequality that is rooted in long-term quality of life assessments.[53] It is axiomatic that the State must evaluate and execute health decisions taken in the context of emergencies by addressing the differentiated impact that such obligations could have on certain sectors of the population in order to respect and ensure the enjoyment and exercise of the rights established in the CRPD without any discrimination.

Protocols denying or omitting access to medical treatment and intensive care, including mechanical ventilation systems and any other forms of life supports, to people with disabilities and older persons in the context of the COVID-19 pandemic may qualify as disability discrimination under Article 2 of CRPD and as age discrimination under Article 2 of the Inter-American Convention on Protecting the Human Rights of Older Persons. In light of this, the former Independent Expert on the enjoyment of all human rights by older persons and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility highlighted in April 2020 that the refusal or omission that affects the right to life of persons with disabilities or older persons may be classified as cruel and inhuman treatment, and therefore constitute a violation of human rights in accordance with international and regional human rights law.[54]

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[50] UN Human Rights Committee, *supra* note 45 at para. 18, 24 ("Persons with disabilities, including psychosocial or intellectual disabilities, are also entitled to specific measures of protection so as to ensure their effective enjoyment of the right to life on an equal basis with others.").

[51] Ubel et al., *supra* note 41.

[52] The Independent Expert on the enjoyment of all human rights by older persons and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, *The right to life of persons with disabilities and older persons infected by Covid-19* (27 April 2020), available at https://www.ohchr.org/en/statements/2020/04/right-life-persons-disabilities-and-older-persons-infected-covid-19#_ftnref9

[53] Bagenstos, *supra* note 29; The Independent Expert on the enjoyment of all human rights by older persons and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, The right to life of persons with disabilities and older persons infected by Covid-19 (27 April 2020), available at https://www.ohchr.org/en/statements/2020/04/right-life-persons-disabilities-and-older-persons-infected-covid-19#_ftnref9

[54] The Independent Expert on the enjoyment of all human rights by older persons and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, *The right to life of persons with disabilities and older persons infected by Covid-19* (27 April 2020), available at https://www.ohchr.org/en/statements/2020/04/right-life-persons-disabilities-and-older-persons-infected-covid-19#_ftnref9.Under article 7 of ICCPR, article 15 of

### F. All human beings must have access to the highest attainable standard of health without discrimination on the basis of disability or age.

International human rights law affirms the right of all people to the highest attainable standard of health equally, without discrimination of any kind. This right protects persons with disabilities and older persons from discrimination in accessing health care services.

Article 25 of the CRPD reaffirms the right of all persons with disabilities to the enjoyment of the highest attainable standard of health *without discrimination*.[55] Article 11 of the Inter-American Convention on Protecting the Human Rights of Older Persons likewise states that older persons retain the right to give free and informed consent on health matters.[56] ICESCR General Comment No. 14 on the right to the highest attainable standard of health noted that an affected individuals biological and socio-economic precondition must be considered when deciding what course of care and treatment would allow the individual to attain their "highest attainable standard of health."[57] Regarding age, the CESCR Committee affirms that State Parties should accord priority to the improvement of the health-care system for older persons, in order to meet its obligation of ensuring availability, accessibility, acceptability and quality of health care for them.[58]

Among other obligations, Article 25 (d) of the CRPD requires States to provide quality health care to persons with disabilities on the basis of free and informed consent, which precludes all forms of substitute decision making.[59] In addition, Article 25 (f) requires States to prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.[60] The reference to food and fluids refers directly to the medical practice of denying health care, health services, food, and fluids on the basis of disability.[61]

The requirement that individuals with disabilities have access to "the highest attainable standard of health without discrimination on the basis of disability" means States must ensure these individuals their equal right to "the same range, quality and standard of free or affordable health care." Likewise, older persons have the right to equal treatment in health care, free from "age

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CRPD, and article 10 of the Inter-American Convention on Protection the Human Rights of Older Persons, such refusal or mission would amount to cruel and inhuman treatment

[55] CRPD, *supra* note 1 at art. 25.

[56] Organization of American States General Assembly, *supra* note 21.

[57] ICESCR, *supra* note1.

[58] Committee on Economic, Social and Cultural Rights, *Consideration of Reports Submitted by States parties under Articles 16 and 17 of the Covenant*, E/C.12/NDL/CO/4-5, United Nations Economic and Social Council, 8 (November 19, 2010) https://www.ecoi.net/en/file/local/1188520/1788_1306165283_e-c-12-nld-co-4-5.pdf.

[59] *Id*. at art 25(d).

[60] *Id.* at art. 25(f).

[61] Penelope Weller, *The Convention on the Rights of Persons with Disabilities and the Social Model of Health: New Perspective*, The Journal of Mental Health Law 74 (2011) 732. *See also* Jacqueline Laing, *Food and Fluids: Human Law, Human Rights and Human Interests* in Christopher Tollefsen, ed. ARTIFICIAL NUTRITION AND HYDRATION (2008), 77.

discrimination, neglect, maltreatment, and violence."[62] States must also ensure that related services are provided to the non-disabled general population.[63]

Article 25 (d) further stresses the importance of raising awareness of the human rights, dignity, autonomy, and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care. A further component of this obligation is to adopt measures which raise awareness about "human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care."[64] This aligns with the obligation in Article 8 requiring States Parties to conduct effective awareness raising to promote a positive image of person with disabilities.[65]

Similarly, Article 19 of the Inter-American Convention on Protecting the Human Rights of Older Persons affirms that older persons have the right to physical and mental health without discrimination of any kind through a variety of state-enforced means. This includes ensuring that State Parties design and implement "comprehensive-care oriented intersectoral public health policies which include promotion, prevention… and care for older persons, to promote enjoyment of the highest level of physical, mental, and social well-being."[66]

### G. Persons with disabilities and older persons enjoy special protection during situations of risk and the obligation to refrain from discrimination on the basis of age, disability, and other factors is still in effect during an emergency.

The adoption of crisis standards of care constitutes an appropriate response for guiding the allocation of scare medical resources by medical professionals during

[62] United Nations Sustainability Group, *supra* note 14.
[63] Research amply demonstrates the multitude of barriers experienced by persons with disabilities in accessing health care services. *See, e.g.*, Tara Lagu, Christine Griffin & Peter K. Lindenauer, *Ensuring Access to Health Care for Patients with Disabilities*, 175 JAMA INTERNAL MED. 157, 157 (2015) ("Patients with disabilities face barriers when they attempt to access health care. These barriers include physical barriers to entering health care establishments, lack of accessible equipment, lack of a safe method for transferring the patient to an examination table, and the lack of policies that facilitate access."); Silvia Yee et al., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity* 39 (2017) ("Negative attitudes toward and assumptions about disabilities have an adverse effect on the health and quality of health care for people with disabilities.").
[64] CRPD, *supra* note 1 art. 25
[65] *Id.* at art. 8. Under Article 8 of the CRPD, States are required to "adopt immediate, effective and appropriate measures" in order: 1) To raise awareness throughout society, including at the family level, of the rights of persons with disabilities; 2) To foster respect for the rights and dignity of persons with disability; 3) To combat stereotypes, prejudices and harmful practices relating to persons with disability in all areas of life; and 4) To promote awareness of the capabilities and contributions of persons with disability.
[66] Organization of American States General Assembly, *supra* note 21.

> a substantial change in usual healthcare operations and the level of care it is possible to deliver, which is made necessary by a pervasive (e.g., pandemic influenza) or catastrophic (e.g., earthquake, hurricane) disaster.[67]

While it is recognized that persons with disabilities and older persons are at greater risk of discrimination in accessing healthcare and life-saving procedures during the COVID-19 outbreak, at the same time,

> rationing and medical triage protocols are typically not subjected to analysis based on an *individual* prognosis as to *immediate survival*, but rather on discriminatory criteria, such as age or assumptions about quality or value of life based on disability.[68]

Article 11 of the CRPD explicitly protects persons with disabilities during situations of risk.[69] It establishes that States parties shall take all possible measures to ensure the protection and safety of persons with disabilities in the response to situations of risk, including pandemics that may be qualified as natural disasters.[70]

The Inter-American Convention on Protecting the Human Rights of Older Persons further states in article 29 that States Parties shall adopt all necessary specific measures to ensure the safety and rights of older persons in situations of risk. States Parties shall also adopt assistance measures specific to the needs of older persons in preparedness, prevention, reconstruction, and recovery activities associated with emergencies.

The global COVID-19 pandemic accordingly falls within the scope of Article 11 of CPRD and Article 29 of the Inter-American Convention on Protecting the Human Rights of Older Persons and thus afford enhanced protection given the vulnerability of persons with disabilities and older persons during situations of risk. This includes the example of pandemics where medical triage protocols and spurious assessments of quality of life may put them at enhanced risk and threaten their right to life.[71]

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[67] *See* Bruce M. Altevogt et al., *Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations* Institute of Medicine Committee on Guidance for Establishing Standards of Care for Use in Disaster Situations (2009). This was the approach urged by the Institute of Medicine in the United States following the outbreak of the H12N1 virus.

[68] UN Sustainable Development Group, *Policy Brief: A Disability-Inclusive Response to COVID 19*, United Nations (May 2020), p. 5-6 https://unsdg.un.org/resources/policy-brief-disability-inclusive-response-covid-19.

[69] CRPD, *supra* note 1 at art. 11.

[70] *Id*. *See also* OHCHR, *Thematic study on the rights of persons with disabilities under article 11 of the Convention on the Rights of Persons with Disabilities, on situations of risk and humanitarian emergencies*, Report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/31/30 30 (November 30, 2015) https://www.ohchr.org/en/documents/thematic-reports/ahrc3130-report-rights-persons-disabilities-under-article-11-crpd.

[71] United Nations Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, *supra* note 2; The Independent Expert on the enjoyment of all human rights by older persons and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, *The right to life of persons with disabilities and older persons infected by Covid-19* (27 April 2020), available at https://www.ohchr.org/en/statements/2020/04/right-life-persons-disabilities-and-older-persons-infected-covid-19#_ftnref9.

Specific obligations arising especially from Article 11 include undertaking measures in all spheres of life to ensure protection for persons with disabilities, including the protection of their access to the highest attainable standard of health without discrimination, provide for general wellbeing and the prevention of infectious diseases, as well as undertake measures to ensure protection against negative attitudes, isolation, and stigmatization that may arise in the midst of the crisis.[72]

## V. Obligations of a Procedural Nature Arising from International Human Rights Law.

International human rights law protects rights in relation to accessing information, transparency in decision-making to facilitate such access, and the participatory rights of consultation in decision-making, especially though not exclusively where interests are at stake that are especially affected.[73]

### A. Notice, information & transparency: Decision-making with regard to the adoption of medical triage protocols is subject to notice and transparency of process.

Access to information is, pursuant to Article (4)3 and Article 21 of the CRPD, a precondition for organizations of persons with disabilities to participate in decision-making that affects them. Furthermore, Article 11 of the Inter-American Convention on Protecting the Human Rights of Older Persons stipulates that older persons have the right to consent, refuse, or suspend medical treatment and to "express their free and informed consent on health matters."[74] This right extends to any stage of the decision-making process, and guarantees that older persons be given clear notice of the steps being taken to treat them.

Such access is therefore a prerequisite to full and meaningful participation in decision making as well as the free expression of opinions, including but not limited to medical decision making. As noted by the Special Rapporteur on the right to the highest attainable standard of health, transparency

> is especially important in times of pandemics because regulations and legislation passed to promote public health in an emergency, but which curtail rights and freedoms, must be closely monitored.[75]

[72] OHCHR, *Thematic study on the rights of persons with disabilities under article 11 of the Convention on the Rights of Persons with Disabilities, on situations of risk and humanitarian emergencies*, Report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/31/30 (November 30, 2015).
[73] CRPD, *supra* note 1 at art. 4(3). *See also* CRPD Committee, *General comment No. 7 on article 4.3 and 33.3 of the convention on the participation with persons with disabilities in the implementation and monitoring of the Convention*, CRPD/C/GC/7**,** CRPD Committee (November 9**,** 2018).
[74] CRPD, *supra* note 1 at 4(3) and 21; *see also* Organization of American States General Assembly, *supra* note 21.
[75] UN Human Rights Council, *supra* note 26.

Further, the right to health under international human rights law encompasses accessibility which also refers to the "accessibility and availability of health information, supported by a right to seek, receive and impart information and ideas concerning health information."[76]

Access to information is likewise a requirement for older persons who "have the right to be well informed about public affairs, including in times of emergencies" and, as an element of the right of access to information, should have "easy, prompt, effective and practical access to information."[77] Older persons experience barriers to community engagement and may not be able to access information.[78] For example, during the COVID-19 pandemic the United Nations Sustainability Group reported that there existed multiple cases where "older persons have not had an opportunity to give consent to medical treatment or have been put under undue pressure to refuse medical treatment in advance."[79]

Persons with disabilities and older persons, as well as, their representative organizations, need to receive the information in accessible formats, including digital formats, and technologies appropriate to all forms of disabilities, in a timely manner and without additional cost.[80] This provision should be sufficiently prior to any consultation to facilitate the formation of an informed opinion.

The CRPD Committee has repeatedly emphasized that States Parties have an obligation to ensure the transparency of the consultation processes, the provision of appropriate and accessible information as well as the early and continuous involvement of persons with disabilities and their representative organizations in decision-making. In particular, States should not withhold information, condition, or prevent organizations of persons with disabilities from freely expressing their opinions in consultations and throughout decision-making processes.

The formulation of medical triage protocols in the absence of providing information to persons with disabilities and their representative organizations, such as through a public notice and comment process, is contrary to the letter and the spirit of the CRPD. This is especially the case in the context of medical triage protocols that too often rest on spurious assessments of quality of life based on disability or age.

### B. Persons particularly affected by crisis standards of care, including medical triage protocols, must be consulted.

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[76] Weller, *supra* note 61.

[77] *See* UN Human Rights Committee, *General comment no. 34, Article 19, Freedoms of opinion and expression*, CCPR/C/GC/34 (September 12, 2011) https://digitallibrary.un.org/record/715606?ln=en#record-files-collapse-header. Equal access to information is important, especially in the context of emergency situations such as the pandemic. It is essential that information about COVID-19 be compiled and made available in accessible and, if necessary, multilingual formats.

[78] Department of Economic and Social Affairs, *Issue Brief: Older Persons and COVID-19, A Defining Moment for Informed, Inclusive and Targeted Response, para. 55*, United Nations (April 6, 2020).

[79] United Nations Sustainable Development Group, *supra* note 14.

[80] United Nations Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, *supra* note 2.

Persons with disabilities, older persons, and others who are disproportionately excluded from decisions regarding healthcare have the right to participate in decisions that affect them. Yet they are often effectively excluded from providing input into decisions regarding the operation of health system systems. Further, persons with disabilities and older persons are underrepresented within the health care profession and face major barriers to participating in the democratic process which regulates health systems.[81]

The main rationale for ending ableism and ageism in health care is to redress these circumstances and take into account the interests and needs of persons with disabilities and older persons in health system decisions.

### i. The right to participate in decision-making is a core human rights for persons with disabilities and older persons.

Consistent with Article 4(3) of the CRPD, as well as the principle of participation reflected in Article 3, States must ensure that persons with disabilities, through their representative organizations, are closely consulted with and actively involved in the planning, implementation, and monitoring of COVID-19 prevention and containment measures.[82]

As noted by the UN Special Rapporteur on the rights of persons with disabilities, "[t]he [CRPD] broadened the significance of the participation of persons with disabilities in decision-making to beyond the scope of political rights, ensuring that they could express their views in all matters affecting them."[83]

This process right clearly extends to decision-making in relation to medical triage protocols which may require them to forgo life-saving treatment because of perceptions about their quality of life. The Convention explicitly requires State parties to consult closely with and actively involve persons with disabilities, through organizations of persons with disabilities, in the *"development and implementation of legislation and policies to implement the present* Convention*, and in other decision-making processes"* concerning issues relating to them.[84]

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[81] *See* Center for Public Representation, *supra* note 25.

[82] CRPD, art. 4(3). *See also General comment No. 7 on article 4.3 and 33.3 of the convention on the participation with persons with disabilities in the implementation and monitoring of the Convention*, CRPD/C/GC/7, CRPD Committee (November 9, 2018) ("The principle of participation is well established in article 21 of the Universal Declaration of Human Rights. It is also reaffirmed in article 25 of the International Covenant on Civil and Political Rights. Participation as a principle and a human right is also recognized in other international and regional human rights instruments, including under article 5 (c) of the International Convention on the Elimination of All Forms of Racial Discrimination, article 7 of the Convention on the Elimination of All Forms of Discrimination against Women, articles 12 and 23 (1) of the Convention on the Rights of the Child…".

[83], *Report of the Special Rapporteur on the rights of persons with disabilities*, *para. 18*, A/HRC/31/62, UN Human Rights Council, (January 12, 2016) https://www.refworld.org/docid/56c581e04.html.

[84] CRPD Committee, *supra* note 82 at para. 18. *See also* UN Human Rights Council, *Thematic study by the Office of the United Nations High Commissioner for Human Rights on participation in political and public life by persons with disabilities*, *para. 15-17*, A/HRC/19/36. (December 21, 2011).

It is important to note that persons with disabilities and older persons, retain the right to participate in decision making regarding their freedom of expression, assembly, and association. As the ICCPR states, all persons are entitled to equal protection under the law "without any discrimination."[85] "[O]ther status" should be read to include age discrimination.[86] Furthermore, older persons are equally entitled to access to public information regarding the COVID-19 response to enable them to make informed decisions and challenge or influence public policies that may impact their rights. Ensuring such access promotes accountability and puts into place much needed safeguards against abuse of power. Principle 7 of the UN Principles for Older Persons affirms:

> Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.[87]

Additionally, the Inter-American Convention for Protecting the Human Rights of Older Persons complements international human rights standards in ensuring the participation of older persons and their groups and associations in decision-making processes by advocating for the creation and strengthening of mechanisms for citizen participation with a view to including their opinions, contributions, and demands.[88]

Given that the voices, perspectives and expertise of older persons in identifying problems and solutions are too often not given consideration, where their interests are especially at stake by decisions under consideration, they must be given the opportunity to be heard.[89]

### ii. The requirement to consult applies to decision-making at all levels.

The CRPD Committee has emphasized that the right to consultation applies in decision-making processes at all levels.[90] Further, this legal obligation extends to the consultation of and with organizations of persons with disabilities, not only in access to public decision-making spaces, but also in respect of ensuring their "partnership, delegated power and citizen control."[91]

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[85] United Nations Treaty Series, *International Covenant on Civil and Political Rights, vol. 999*, art. 25, 26, UN General Assembly (December 16, 1966).
[86] Marthe Fredvang & Simon Biggs, *The Rights of Older Persons: Protection and gaps under human rights law*, The Centre for Public Policy (August 2012) https://social.un.org/ageing-working-group/documents/fourth/Rightsofolderpersons.pdf
[87] *United Nations Principles for Older Persons*, Principle 7, UN Ga. Res. 46/91 (Dec. 16, 1991) https://www.ohchr.org/en/instruments-mechanisms/instruments/united-nations-principles-older-persons.
[88] *See* Inter-American Convention on Protecting the Human Rights of Older Persons, art. 27 (d), Organization of American States General Assembly (January 11, 2017), https://www.oas.org/en/sla/dil/inter_american_treaties_a-70_human_rights_older_persons.asp.
[89] UN Human Rights Council, *supra* note 2 at para. 57. *See also* Department of Economic and Social Affairs, *supra* note 75.
[90] CRPD Committee, General Comment No. 7, *supra* note 68. Prior consultations and engagement with organizations of persons with disabilities at all stages of public decision-making, including before the adoption of legislation, policies and programmes that affect them, is a prerequisite.
[91] *Id. See also* UN Human Rights Council, *Report of the Special Rapporteur on the rights of persons with disabilities, Access to rights-based support for persons with disabilities*, para. 63, A/HRC/34/58 (December 20, 2016).

The CRPD Committee, together with the UN Special Envoy on Disability and Accessibility called for States to adopt measures "to appropriately respond to the COVID-19 pandemic, ensuring inclusion and the effective participation of persons with disabilities."[92] The Independent Expert on the enjoyment of all human rights by older persons further insisted that national health policies regarding COVID-19 must be based on assessments of the needs of older persons and that they should be carried out in consultation and full participation of older persons.[93] Efforts to involve persons with disabilities and older persons in the decision-making processes are essential to result in better decisions and more efficient outcomes, as well as, they promote citizenship, agency, and empowerment.[94]

It is particularly important for States to take into consideration the rights and concerns of persons with disabilities and older persons when considering legislation and policies related to bioethics, age and disability. Consistent with the work of the UN Special Rapporteur and the UN Independent Expert regarding the COVID-19 pandemic, important components of trust are transparency and the inclusion of civil society in governance and policy processes.

People who are representatives of civil society, including disability rights activists and advocates for older persons' human rights should be able to access information and undertake their work for the promotion and protection of human rights, including the right to health, during pandemics. They likewise should not suffer from criminalization, stigmatization, or harassment of any sort because of the work that they do. This is especially important in times of pandemics because regulations and legislation passed to promote public health in an emergency, but which curtail rights and freedoms, must be closely monitored.[95]

### iii. Persons with disabilities and older persons are experts in their own lives.

Persons with disabilities and older persons are the real experts on their own lives and thus have the right to participate in the decision-making process and should be provided with disability and age-appropriate support for that purpose.[96]

In the protection context, including in situations of risk posed by a global pandemic, the interests, rights, and personal circumstances of individuals with disabilities and older persons must be given

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[92] *See, e.g., General comment No. 7 on article 4.3 and 33.3 of the convention on the participation with persons with disabilities in the implementation and monitoring of the Convention,* CRPD/C/GC/7**,** CRPD Committee (November 9**,** 2018). In its concluding observations, the CRPD Committee has consistently reminded States parties of their duty to closely and timely consult with, and actively involve, persons with disabilities, through their representative organizations, including those representing women and children with disabilities, in the development and implementation of legislation and policies to implement the Convention and in other decision-making processes.

[93] UN Human Rights Council, *supra* note 2, para. 39

[94] UN Human Rights Council, *supra* note 26.

[95] UN Special Rapporteur, *supra* note 26 at para. 18. *See also* UN Human Rights Council, *supra* note 2 at para. 58.

[96] Catalina Devandas-Aguilar, *Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities*, A/72/133, United Nations General Assembly (July 14, 2017). *See also* UN Human Rights Council, *supra* note 2 at para. 58. ("[T]he voices, perspectives and expertise of older persons in identifying problems and solutions" are insufficiently included in policymaking "particularly in areas in which older persons are affected by the decisions under consideration.")

due consideration. Thus, beyond receiving information in advance of decision-making where interests are affected, States must closely consult with and actively involve persons with disabilities, older persons, and their representative organizations. In the context of medical ethics and crisis care stands, the participation of persons with disabilities and older persons in the work of national bioethics committees should be advanced, a practice followed in various States.[97]

The lack of participation by persons with disabilities on medical committees results in decisions without considering their impact on persons with disabilities in decisions regarding medical triage and other protocols when their views ought to be given due weight.[98] Multi-stakeholder inputs are imperative given the risk of intersectional discrimination in relation to medical triage protocols, of which the US State of North Carolina can be viewed as a model.[99] States should guarantee that they are not only heard as a mere formality or as a tokenistic approach to consultation but that they views are considered and taken into account.

## VI. Conclusions

International and regional human rights law prohibits the rationing of life-saving treatment based on the judgment of the effects of disability and age on a person's quality of life.

Likewise, medical triage protocols that would effectively permit the denial of life-saving treatments to individuals who have a distinct pre-existing disability may amount to human rights violations.

In the context of an actual triage situation where medical treatment is constrained and resources are unable to accommodate all people seeking care, it may indeed be necessary for the medical system to make extremely difficult choices about the allocations of scarce resources. However, triage procedures needed in such situations must be in line with human rights standards.

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[97] *See* Bagenstos, *supra* note 29 at p. 9. For example, in Sweden an expert nominated by the Swedish Disability Rights Federation represents persons with disabilities in the National Council on Medical Ethics. As aptly put by Bagenstos, "[A]llowing scarcity of ventilators, while imposing the life-or-death costs of that scarcity most heavily on disabled people—bespeaks a failure of democratic legitimacy."

[98] Christopher Newell, *Disability, Bioethics, and Rejected Knowledge*, 31 JOURNAL OF MEDICINE AND PHILOSOPHY 269-83 (2006).

[99] North Carolina Department of Health and Human Rights, North Carolina Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic, State of North Carolina (January 11, 2021) https://covid19.ncdhhs.gov/media/1117/download. As noted in North Carolina's Protocols: "The recommended protocol has been developed in extensive consultation with state experts in several clinical specialties (including intensive care, pediatrics, palliative care, emergency medicine, family medicine, psychiatry, infectious disease, nephrology, and anesthesiology), nursing, spiritual care, ethics, law, and public health. Advisors also included representatives from community and advocacy groups representing racial and ethnic minorities, vulnerable populations, people with disabilities, older adults, and faith communities. The role of the convening organizations (NCIOM, NCMS, and NCHA) was to facilitate discussion and synthesize feedback from these groups to inform the development of a recommended protocol consistent with other state and federal protocols for allocating scarce critical resources during a pandemic."

The denial of potentially lifesaving treatments to individuals on the basis of their disability or age, when such individuals stand to benefit from them, is explicitly and implicitly prohibited under international human rights law.

Thus, medical triage protocols that rest on an assumption about an individual's quality of life inevitably fail to satisfy the obligations of States under international human rights law, as seen on numerous grounds outlined herein.