



Human Rights Commission  
Te Kāhui Tika Tangata

# National Ethics Advisory Committee: Ethical Framework for Resource Allocation in Times of Scarcity

Submission of the Human Rights Commission

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## Contents

Human Rights Commission Submission on Ethical Framework for Resource Allocation During Times of Scarcity.....	3
Introduction .....	3
Te Tiriti o Waitangi.....	3
Human rights .....	4
Human Rights Standards .....	4
Equality and Non-discrimination .....	5
Intersectionality.....	6
A focus on Equity .....	6
Indigenous Health Inequities .....	6
Participation and accountability.....	7
Ethical Principles.....	7
Tensions between principles .....	7
Allocation principles .....	8
Te Tiriti o Waitangi principles.....	8
Decision-making process .....	9
Specific considerations Rights of Persons with Disabilities and Older Persons .....	10
Exposure to risk .....	10
Non-discrimination .....	10
Participation.....	11
Accessibility.....	11
Older Persons.....	12
Summary .....	12
Endnotes .....	14

# Human Rights Commission Submission on Ethical Framework for Resource Allocation During Times of Scarcity

## Introduction

The Human Rights Commission welcomes the opportunity to provide this submission to the National Ethics Advisory Committee (the committee) on the Ethical Framework for Resource Allocation in Times of Scarcity.

The Commission commends the committee for its explicit recognition of Te Tiriti o Waitangi, Human Rights and Equity within the framework. While the framework is concerned with a specific set of circumstances, we warmly welcome the acknowledgement that these principles and related decisions sit within a wider context and require consideration of determinants of health and drivers of inequity.

A human rights-based approach to health is concerned with process as well as outcome and we also commend the recognition of the importance of decision-making processes. The rights to participation and a process of independent accountability are both particularly critical, when discretionary powers are being exercised over what may be matters of life or death.

We suggest the framework would be strengthened by giving greater prominence to Te Tiriti, and elaborating further on its application in practice, both in the examples and in decision making. We consider that it would also benefit from an expanded consideration of relevant human rights standards, and in providing greater clarity for decision makers of the legally binding international and domestic human rights obligations they are bound by at any time, including during times of emergency.

We make a range of suggestions to strengthen the human rights-based approach and suggest that NEAC could review the framework through the lens of the extent to which it advances or impedes, the right to enjoyment of the highest attainable standard of physical and mental health, without discrimination.

Although our comment is focused on the current Covid-19 specific framework, the human rights-based approach recommended would be equally and highly relevant to a revision of the broader focused “Getting Through Together Ethical Values for a Pandemic.”

## Te Tiriti o Waitangi

The Commission welcomes the discussion in the document of Te Tiriti o Waitangi<sup>i</sup> and Te Tiriti o Waitangi principles<sup>ii</sup> as part of the ethical framework. The Commission considers that it is crucial

that COVID-19 responses and decisions are firmly grounded in Te Tiriti, including that: Māori as Tiriti-partners share in decision-making; Māori are able to exercise rangatiratanga and lead solutions; and equity for Māori is central.

While supportive of many of the points raised in these sections of the paper, the Commission suggests the document would benefit from greater integration of and focus on Te Tiriti throughout. We recommend that further discussion is included to flesh out the application of Te Tiriti principles to the examples and other substantive elements of the paper.

As discussed further below, we submit that a Tiriti-based approach supports a greater weighting be given to Te Tiriti and equity considerations in resource allocation decisions. As discussed, and recommended by the Waitangi Tribunal in the *Hauora* report, Crown Tiriti obligations and the successive failures to uphold these that have contributed to entrenched Māori health inequities, demand a firm and deliberate commitment by the Crown to advancing Māori health equity.<sup>iii</sup> How this commitment is given effect in resource allocation decisions, would be a useful area to explore further in the document.

We are also of the view that, while the document includes some positive statements on the relevance of tikanga and mātauranga Māori (for example, at p 12), there is little actual discussion of these issues, of fundamental Māori values themselves or their application in ethical frameworks and decision-making. We support the statement, on page 12, that tikanga and mātauranga Māori should not merely be considered alongside a suite of other values but should be fundamental reference points for challenging other values. In supporting a Tiriti-based approach, we submit that tikanga and mātauranga should be at the heart of the framework, and as such warrant greater attention in the document.

## Human rights

### Human Rights Standards

As noted in our recent report, *Human Rights and Te Tiriti o Waitangi: COVID-19 and Alert Level 4 in Aotearoa New Zealand*, the rights to life, health protection and health care without discrimination place obligations on the government to do all it can to respond effectively and equitably to COVID-19.<sup>iv</sup>

We therefore welcome the recognition of the importance of human rights in the framework and the placing of dignity, as a core human rights value, as the foundation.

We particularly welcome the specific reference to the Universal Declaration on Human Rights (UDHR) at the beginning of the document, and highly commend the principle of non-discrimination being included in the allocation principles table, informed by General Comment 20 of the International Committee on Economic Social and Cultural Rights (ICESC).

We would recommend that these sections would be strengthened by:

Explicit mention of the International Bill of Rights. This collection of legally binding human rights instruments includes the UDHR, International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). It is within the latter Treaty, that the more apt articulation of the Right to the Highest Attainable Standard of Health can be found, which sets out the steps to be taken by States to realise this right including, to prevent, treat, and control epidemic and other diseases.

and

Referencing General Comment 14 of the Committee on Economic social and cultural rights which focuses specifically on the right to the enjoyment of the highest attainable standard of physical and mental health. This General Comment clarifies that among State obligations which require immediate effect in relation to this right, is that it is exercised without discrimination.<sup>v</sup> It also summarises four essential and interrelated elements for implementing this right. Availability, Accessibility, (non-discrimination, physical and, economic accessibility) Acceptability (ethically and culturally) and Quality.<sup>vi</sup>

### Equality and Non-discrimination

We consider that human rights would be better positioned as the bedrock foundation for the framework, rather than as a subset of equity as it is currently positioned. This would serve to cohere the various core human rights values referenced throughout the document such as dignity, respect, procedural fairness and transparency into a more comprehensive human rights-based approach.

A Human Rights Based approach to Health aims to develop capacity for duty bearers to meet their obligations and empower rights holders to effectively claim their rights.<sup>vii</sup> It also places importance on both process and outcomes so in this regard is equally relevant to decision making bodies and processes, as it is to the principles.

We suggest therefore that the framework could better fulfil such an approach by setting out briefly but more explicitly those obligations and rights. Specifically, although the section on equity acknowledges the potential for discrimination, it does not expressly refer to the fundamental rights of equality and non-discrimination, which are highly relevant to an allocation framework.

Several human rights treaties apply across the whole health system and give guidance to assist the realisation of the right to health on a non-discriminatory basis for populations who may experience barriers and differential outcomes. These include:

- a. Convention on the Rights of Persons with Disabilities
- b. Convention on the Rights of the Child
- c. Convention on the Elimination of All Forms of Racial Discrimination
- d. Convention on the Elimination of All Forms of Discrimination Against Women
- e. International Covenant on Economic, Social and Cultural Rights

#### f. International Covenant on Civil and Political Rights

This right can also be found in the United Nations Declaration of the Rights of Indigenous Persons (Article 24 (2)). Citation of these instruments would support considerations of intersectionality.

#### Intersectionality

We affirm the acknowledgement of the ways in which disadvantage can accrue across the intersection of diverse identities or spheres of marginalisation. The focus on Ableism is highly relevant, and we recommend that:

The intersection with racism, and ageism be expanded to include the structural inequities referred to in the Increasing Risk section, to include, sexual orientation, gender identity and expression, and sex characteristics (SOGIESC) and socioeconomic status, as well as the prohibited grounds of discrimination set out in the Human Rights Act 1993.

#### A focus on Equity

We applaud the committee's nuanced understanding of the potential for a pandemic to exacerbate existing inequities and that therefore differential approaches are required for the achievement of equitable outcomes.

A focus on equity accords with a human rights approach. Contrary to common misinterpretation, differential treatment is not inconsistent with the right to equality and non-discrimination, in fact differential treatment is not only permitted, but required, provided it can be justified on objective and rational grounds.<sup>viii</sup>

As a core social institution, the health system both reflects and reinforces social norms, including those that serve to exclude or marginalise.<sup>ix</sup> As noted, pandemic responses may act to either entrench or minimise inequity and we welcome the advice to decision makers that this must be a consideration in their allocation decisions.

#### Indigenous Health Inequities

We support a particular focus on indigenous health inequities, however, note that the content in this section focuses somewhat narrowly on health conditions. The earlier section on exposure to determinants of health recognises that wider determinants such as the distribution of power and resources contribute to inequity, and this section would benefit from a clearer link to those determinants.

We also suggest adding reference to the United Nations Declaration on the Rights of Indigenous Peoples<sup>x</sup> which as referred to above complements Te Tiriti o Waitangi in affirming the rights to self-determination, to traditional knowledge and the equal right to the highest attainable standard of physical and mental health.

While supportive of this section of the paper, we submit that it does not quite convey the extent and urgency of the situation, or the entrenched nature of the inequities. Reference to the Waitangi

Tribunal’s Hauora report may be helpful, for example, the Tribunal’s point that “the health inequities experienced by Māori compel an urgent, and thorough, intervention”.<sup>xi</sup> Furthermore, it may also be noted that these inequities are themselves the result of a myriad of Tiriti breaches, warranting purposeful action from the Crown. The weight of these past injustices behoves the Crown to actively take steps and seek opportunities to provide just solutions.

### Participation and accountability

As referred to earlier, a Human Rights based approach to health, is equally concerned with process which must be founded in the fundamental right to free active and meaningful participation in decisions, by those affected by them.

As considerable discretion is afforded to the proposed decision-making group, we suggest that not only is the obligation to uphold the right to participation set out strongly, but also the need for robust and independent accountability.

We return to this in the section focused on the decision-making process and decision-making group.

## Ethical Principles

### Tensions between principles

Balancing of rights is inherent to a human rights approach. It is one that therefore has considerable value to offer in a framework such as this where it is recognised that there may be a tension, or a balance to be struck, between principles.

By way of illustration the committee, may wish to review a finding from the South African Constitutional Court. In essence this case carefully balanced international human rights and domestic constitutional protections to life, health care and emergency treatment and found that the Ministry of Health was justified in rationing, or denying access to publicly funded life prolonging treatment, in this case dialysis, because in the context of resource constraint, the eligibility guidelines to manage access were reasonable, and the process of decision making a fair application of them.<sup>xii</sup>

The New Zealand Courts have also considered the balancing of public health interests and the collective right to health against individual rights, albeit in a different context. In *New Health NZ Ltd v South Taranaki District Council & Ors* [2017] NZSC 59, the Supreme Court dismissed a claim that the fluoridation policy of a local authority breached the right to refuse medical treatment under the New Zealand Bill of Rights Act. In doing so the Court found the evidence of the public health benefits justified the limitation of the individual right in that case. However, a scenario regarding scarcity of resource will of course require consideration of a fundamentally different set of human rights and ethical considerations.

As acknowledged in the framework, to meet obligations and confer legitimacy on decisions there must be careful deliberations. We suggest this be supported by reference to human rights approach which necessitates, fair, reasoned, robust and transparent decision making as well as independent scrutiny.

International ethical guidelines, such as the WHO's 'Ethics and COVID-19: resource allocation and priority-setting' provide relevant frameworks for prioritisation and decision-making that align with a human rights approach and key principles of Transparency, Inclusiveness, Consistency and Accountability.<sup>xiii</sup>

## Allocation principles

### **All People are deserving of Care**

While the application section sets out the right to non-discrimination, we suggest that this obligation would be reinforced by the principle being formulated as: All people are equal in rights to care and referenced to Article 12 of ICESCR. We would also suggest this rights-based formulation be applied instead of the 'equal moral worth' formulation at Page 7 with regard to increasing risk.

### **Prioritising the people most in need**

We support the focus on restoration of health for those most in need and suggest that the addition of direct reference to Article 12 of ICESCR and General Comment 14 would provide a deeper and stronger rationale for this approach than solely the Rio Political Declaration on Social Determinants of Health.

### **Equity**

As stated above we strongly support a focus on equity which accords with the right to the highest attainable standard of health.

## Te Tiriti o Waitangi principles

Honouring Te Tiriti and human rights commitments is vital to ensure an effective response to COVID-19 and to prevent the erosion of trust and confidence within Crown-Māori relationships. As outlined earlier, we support the inclusion of Te Tiriti principles and stress they are complimentary and mutually reinforcing with human rights principles. This could be highlighted through the inclusion of specific reference to the United Nations Declaration on the Rights of Indigenous Peoples ("UNDRIP"), which reinforces many relevant rights including to self-determination, to participation in decision making and to the equal right to the highest attainable standard of health.

The Commission endorses the fundamental importance of tino rangatiratanga and mana motuhake. These inherent rights align with the fundamental right to self-determination and are affirmed in the UNDRIP.<sup>xiv</sup> In addition to Māori being key decision-makers, we suggest that it may be helpful to note in the 'application' column, that this may also require transfer of resources directly to Māori Tiriti partners, rather than distribution through Crown agencies/services. The practical application of this principle could also be usefully elaborated in the 'Making decisions' section on pp 11-13. For example, we suggest that a decision-making body should reflect Tiriti partnership, enable rangatiratanga, and be required to not only take into account, but to actively uphold and give effect to Te Tiriti.

In the discussion of the principle of active protection, we strongly agree that this may require a prioritising of resources to protect Māori health. We suggest that other Tiriti principles, including partnership and equity, also require priority to be given to Māori health, in order to address the power

and resource imbalance inherent in the Crown/Māori partnership, and to address entrenched inequities.

We urge provision of greater clarity in the partnership section, recognising that Iwi and hapū are the primary partners, and for example, should be selecting representatives (i.e., rather than the Crown identifying who it works with).

We note in this section, that equity, one of the recommended sets of Tiriti principles outlined in the Waitangi Tribunal's *Hauora* report has not been included in this table. We suspect that this is because equity is one of the resource allocation principles outlined on page 7. However, in that section the Tiriti context and implications are not discussed. We submit that these aspects warrant specific focus and discussion, and that equity should be included in both tables.

Several Waitangi Tribunal reports have discussed how current inequities heighten Crown obligations to act in partnership and to actively protect Māori rights.<sup>xv</sup> This includes the need to prioritise resources. The *Hauora* report includes an overarching recommendation that “the Crown commit itself and the health sector to achieve equitable health outcomes for Māori”.<sup>xvi</sup> The Commission submits that this recommendation, and its application to resource allocation, needs to be more clearly reflected and discussed in the Tiriti principles section.

Further, it is our view that the presence of equity amongst both sets of principles highlights its fundamental importance and reflects the significance to be afforded it when considering and balancing the various principles. We submit that in a resource allocation setting the principle of equity, and the goal of advancing Māori equity, should be given particular priority.

The *Hauora* report clearly highlights the degree that systemic inequities are reflected in persistent health disparities for Māori. Against this backdrop, we suggest that there is an added weight of responsibility to ensure that resource allocation decisions do not perpetuate or exacerbate inequities. In our view, more is required than simply overlaying an ethical framework upon an inequitable system – there is a need to actively and explicitly combat inequity. We submit that it would be helpful to explore these issues further in the report, giving particular focus to how Tiriti obligations may require particular prioritising of resources.

## Decision Making and Accountability

### Decision-making process and decision-making group

We strongly endorse the core human rights and Te Tiriti values outlined in relation to the decision-making process. However, we consider that they are not given true effect due to the degree of discretion afforded to health institutions in deciding the composition of their own group and in merely ‘including’ the perspectives of various groups, rather than underscoring Tino Rangatiratanga, and the rights of participation.

As noted earlier, in a human rights-based approach, process is critical, and this is one that requires

transparency and independence.

We therefore suggest that the framework provides stronger imperatives that human rights and Te Tiriti principles are applied in determining both the composition, operation, and independent oversight of any group. “What human rights requires is a process of meaningful democratic deliberation, which includes those who are or will be affected by the decisions taken, with all of the challenges that such deliberation entails in practice.”<sup>xvii</sup>

It would be helpful to clarify whether the terms allocation and triage are being used interchangeably, and therefore whether more than one decision making group is operating throughout the allocation process.

We suggest that the framework could signal the requisite competencies for a decision-making group, including but not limited to, Mātauranga Māori, Human Rights, and Ethics and/or the requirement for training to build such competencies.

## Specific considerations Rights of Persons with Disabilities and Older Persons

### Exposure to risk

The United Nations High Commissioner for Human Rights has stated, *“our efforts to combat this virus won't work unless we approach it holistically, which means taking great care to protect the most vulnerable and neglected people in society, both medically and economically. Such people include those on low incomes, isolated rural populations, people with underlying health conditions, people with disabilities and older people living alone or in institutions.”*<sup>xviii</sup>

Her views are underscored by the Special Rapporteur on Rights of Persons with Disabilities who has noted that around the world disabled people are feeling left behind.

A range of factors place disabled people at higher risk of exposure to and from the virus for example, containment measures, social isolation and physical distancing may be impossible for some disabled people who rely on support essential for survival such as to eat or to wash. Hence the Special Rapporteurs call that, *“States must take additional social protection measures to guarantee the continuity of support in a safe manner throughout the crisis”*.<sup>xix</sup>

### Non-discrimination

We acknowledge, that some of these factors are reflected in the framework, through recognition of possible discrimination, and in particular the potential impact of ableism on allocation decisions. But because the health system has been a source of significant discriminatory action towards disabled people, (for example performing non-consensual sterilisation, the Ashley treatment, or forced medicating), we suggest further weight could be given to ensuring non-discrimination by drawing on guidance from the Committee on the Rights of Persons with Disabilities (CRPD) in General Comment

## 6 Equality and non-discrimination.<sup>xx</sup>

Non-discrimination appears both as a principle and as a substantive article in the Convention on the Rights of Persons with Disabilities because it is so critical to addressing marginalisation experienced by disabled people.

The General Comment provides further evidence that non-discrimination not only does not prohibit differential treatment but requires it in the form of reasonable accommodations when it is necessary to ensure equitable outcomes. It also clarifies that non-discrimination extends to ensuring that health services are not denied on the basis of disability and that informed consent processes, and the information on which consent is based, are accessible and participatory.

We suggest that the committee, incorporates guidance about Covid-19 and the rights of persons with disabilities compiled by the United Nations, in which they provide examples of good practice from various jurisdictions. This includes guidelines that stress disability, or alternative descriptions such as frailty, or reliance on support, must not be used as a proxy determinant of clinical prognosis that affects allocation decisions.<sup>xxi</sup>

### Participation

In addition, we suggest incorporating guidance from the CRPD Committee as to the implementation of the rights of disabled people to participate in decisions affecting them. Illustrating the implementation of Article 4.3 of the CRPD, it outlines that to “closely consult with and actively involve persons with disabilities through their representative organisations is an obligation under international human rights law... ensures that the knowledge and life experiences of persons with disabilities are considered when deciding upon new legislative, administrative, and other measures. This includes decision-making processes, such as general laws and the public budget or disability-specific laws, which might have an impact on their lives.”<sup>xxii</sup>

This guidance also outlines the need to adequately resource participation if this right is to be enjoyed.

For indigenous persons with disabilities this right is mutually reinforced across Article 4.3 of the CRPD and Article 18 and 22 of the United Nations Declaration on the Rights of Indigenous Peoples. In the latter, the right to participate, specifically outlines, that this be through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own indigenous decision-making institutions.

If it has not already done so, we suggest that the committee proactively seeks review of the framework by disabled and older people and groups identified as experiencing structural disadvantage, rather than rely solely on a universal consultation process.

### Accessibility

Facilitating participation would also require the provision of the consultation document and the finalised guidelines in culturally appropriate and accessible formats such as Te Reo, Easy Read, plain language, Braille, Audio, and New Zealand Sign Language video. These actions would model active application of the principles by the committee.

It would similarly give greater effect to the duties towards disabled people during times of risk and humanitarian emergency set out in Article 11 of the CRPD which require *“Active involvement of people with disabilities in the development, implementation and monitoring of emergency-related legislation and policies, and the establishment of priorities for aid distribution.”*

Fulfilling these rights would be assisted by a point made earlier, that the NEAC, could strongly encourage that decision-making groups be competent in or undergo training in, Te Tiriti and human rights including their application for specific populations such as disabled people.

## Older Persons

Many of the risks, and the rights outlined in this section, apply equally to older persons who form a significant part of the 24% of the population that are identified as disabled. Although not all older persons are disabled, nor is there a human rights treaty dedicated solely to the rights of older persons, the universal rights to non-discrimination to the highest attainable standard of physical and mental health and to participation include older persons.

In a Covid-19 specific framework, age, as a demographic feature associated with risk, potential discrimination and inequity, should be specifically mentioned on every occasion that structural barriers are considered, such as in Table 3.

These concerns are clearly reflected in recent statements by the Special Rapporteur on the Rights of Older persons including in which “she stressed the urgent need for a holistic human rights approach for older persons that ensures equal realization of all their rights, including access to health care.

"I am deeply concerned that decisions around the allocation of scarce medical resources such as ventilators in intensive care units may be made solely on the basis of age, denying older persons their right to health and life on an equal basis with others.

"Triage protocols must be developed and followed to ensure such decisions are made on the basis of medical needs, the best scientific evidence available and not on non-medical criteria such as age or disability.

"Older persons have become highly visible in the COVID 19 outbreak but their voices, opinions and concerns have not been heard. Instead, the deep-rooted ageism in our societies has become even more apparent”<sup>xxiii</sup>

Hence, we would urge that the rights to equality and participation for Older persons would also be more strongly expressed.

## Summary

There is much to commend in the framework. It summarises many relevant Te Tiriti and human rights

standards and gives due acknowledgement of the criticality of deliberation and due process.

We submit that the suggestions and resources we have offered will serve to clarify and strengthen protections for rights holders, illuminate obligations for duty bearers and assist in managing the complex balancing of rights that may arise in circumstances of scarcity.

We are more than willing to assist the committee further in its deliberations.

## Endnotes

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- <sup>i</sup> At pp 2-3.
- <sup>ii</sup> At pp 8-9.
- <sup>iii</sup> Waitangi Tribunal, (2019), [Hauora Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry](#), Wai 2575, at p 161-164.
- <sup>iv</sup> [Human Rights and Te Tiriti o Waitangi: COVID-19 and Alert Level 4 in Aotearoa New Zealand](#) P4
- <sup>v</sup> [CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health \(Art. 12\)](#) Para 30
- <sup>vi</sup> *Ibid.*, Para 12
- <sup>vii</sup> [A Human Rights Based Approach to Health](#) World Health Organisation
- <sup>viii</sup> [Right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Report of the Special Rapporteur to UN General Assembly, 62 session, 8 August 2007, paras 11-32.](#)
- <sup>ix</sup> [Taking Equality Seriously: applying Human Rights Frameworks to Priority setting in Health](#) Alicia Ely Yamin, *Ole Frithjof Norheim Human Rights Quarterly*, Volume 36, Number 2, May 2014, pp. 296-324(Article)
- <sup>x</sup> <https://www.ohchr.org/EN/Issues/IPeoples/Pages/Declaration.aspx>
- <sup>xi</sup> Waitangi Tribunal, (2019), [Hauora Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry](#), Wai 2575, at p 163.
- <sup>xii</sup> [Soobramoney v Minister of Health South Africa Constitutional Court](#)
- <sup>xiii</sup> World Health Organisation, [Ethics and COVID-19: resource allocation and priority-setting](#)
- <sup>xiv</sup> Articles 3, 4, 5.
- <sup>xv</sup> Waitangi Tribunal, (2019), [Hauora Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry](#), Wai 2575, at p 32-33, 164.
- <sup>xvi</sup> *Ibid.*, at p 164.
- <sup>xvii</sup> [Taking Equality Seriously: applying Human Rights Frameworks to Priority setting in Health](#) Alicia Ely Yamin, *Ole Frithjof Norheim Human Rights Quarterly*, Volume 36, Number 2, May 2014, pp. 296-324(Article) p 324
- <sup>xviii</sup> [UN High Commissioner for Human Rights Michelle Bachelet, 6 March 2020](#)
- <sup>xix</sup> [Special Rapporteur Rights of Persons with Disabilities COVID-19: Who is protecting the people with disabilities? Statement 17 March 2020](#)
- <sup>xx</sup> [Committee on the Rights of Persons with Disabilities General comment No. 6 \(2018\) on equality and non-discrimination](#)
- <sup>xxi</sup> [Covid 19 and the rights of persons with disabilities: Guidance 1](#)
- <sup>xxii</sup> *Ibid.*, at para 18.
- <sup>xxiii</sup> [Unacceptable” – UN expert urges better protection of older persons facing the highest risk of the COVID-19 pandemic](#)