

55 University Avenue, 15th Floor Toronto, Ontario M5J 2H7 www.archdisabilitylaw.ca

(416) 482-8255 (Main) 1 (866) 482-ARCH (2724) (Toll Free) (416) 482-1254 (TTY) 1 (866) 482-ARCT (2728) (Toll Free) (416) 482-2981 (FAX) 1 (866) 881-ARCF (2723) (Toll Free)

Sent via email to COVIDUpdates@ontariohealth.ca

July 20, 2020

Joint Centre for Bioethics University of Toronto 155 College Street, Suite 754 Toronto, ON M5T 1P8 Canada

Dear Ms. Gibson and Mr. Smith:

Re: ARCH Disability Law Centre Submissions and Recommendations Regarding Ontario's Triage Protocol Draft dated July 7, 2020

The within document is the written submission of ARCH Disability Law Centre (ARCH) in response to a review of the draft Triage Protocol dated and delivered July 7, 2020¹ and from the discussion held at the July 15, 2020 Roundtable, co-convened by the Bioethics Table and the Ontario Human Rights Commission.² We provide these submissions in addition to our previous submissions dated May 13, 2020,³ and not in substitute of them.

.

¹ Critical Care Triage for Major Surge in the COVID-19 Pandemic: Updated Recommendations, delivered and dated July 7, 2020 ["Triage Protocol 2"].

² ARCH would like to especially and sincerely thank members of its Advisory Committee for engaging in extensive discussion and providing thoughtful guidance and expertise on the important issues raised by the Triage Protocol. ARCH's Advisory Committee, in alphabetical order, includes: Chris Beesley, Executive Director at Community Living Ontario, Laura LaChance, Interim Executive Director at Canadian Down Syndrome Society, Trudo Lemmens Professor, Scholl Chair in Health Law and Policy at University of Toronto Law School, David Lepofsky, Chair of the AODA Alliance, Leanne Mielczarek, Executive Director of Lupus Canada, Elizabeth Mohler, Board Member at Citizens With Disabilities – Ontario, Roxanne Mykitiuk, Disability Law, Health Law, Bioethics and Family Law Professor at Osgoode Hall Law School, Tracy Odell, Executive Director of Citizens with Disabilities – Ontario, Dr. Homira Osman, Director of Knowledge Translation & External Engagement at Muscular Dystrophy Canada, and Wendy Porch, Executive Director at the Centre for Independent Living Toronto.

³ ARCH submissions, dated May 13, 2020 ["ARCH May Submissions"] available online here: https://archdisabilitylaw.ca/wp-content/uploads/2020/05/ARCH-Lttr-re-Clinical-Triage-Protocol-May-13-2020-PDF.pdf

Background

While Triage Protocol 2 demonstrates some improvement over the first version,⁴ there continues to be alarming issues that must be rectified to ensure that any response to a surge in COVID-19 cases does not adversely and disproportionately impact persons from marginalized communities including but not limited to persons with disabilities, elderly persons, Indigenous persons, Black persons and persons from other racialized communities. Representatives from various disability communities and organizations have made clear their concerns with both iterations of the Triage Protocol.

For ease of reference, the submissions that follow are divided into three sections. First, these submissions address the framework of Triage Protocol 2 – this captures the issues related to the overall structure and guiding principles of the document. The second section addresses procedural issues – this includes issues with the process of the development of the Triage Protocol and the lack of transparency. The third section addresses substantive issues, which includes the use of Clinical Frailty Scale as a metric to assess patients, the suggestion to use random selection as a method of fairness, and the importance of ensuring that a dispute resolution mechanism is in place.

ARCH submits the following recommendations to ensure that Triage Protocol 2 does not have an adverse impact on persons with disabilities:

- 1. **Non-discrimination** must be a guiding principle in its own right to ensure appropriate weight is given to human rights in triage decisions.
- 2. The Triage Protocol must **not rely on medical utility** as its primary guiding principle, as it leads to adverse consequences for persons with disabilities, and fails to consider systemic health discrepancies.
- 3. The framework must shift from a focus on the **intention not to discriminate** to **whether adverse impact (discrimination) flows** from the approaches embodied in Triage Protocol 2.

⁴ Critical Care Triage for Major Surge in the COVID-19 Pandemic dated March 28, 2020.

- Ontario Health must communicate to every hospital and medical association/organization that the Triage Protocol dated March 28, 2020 is not be relied upon or implemented.
- Clear language and plain language versions of all drafts and the final version
 of the Triage Protocol are to be produced and distributed widely so that all
 relevant stakeholders are able to understand the information and provide
 feedback.
- Wider consultations are to be undertaken by the Bioethics Tables to ensure that the
 perspectives of persons with lived experience from marginalized and
 disproportionately impacted communities are heard and inform the drafting of the
 Triage Protocol.
 - 7. The Triage Protocol must not rely on the Clinical Frailty Scale in any capacity.
 - 8. The Triage Protocol must eliminate eligibility criteria that considers survivability beyond the acute COVID-related event.
 - 9. The Triage Protocol must provide clear and specific guidance and **direction as to how random selection should be carried** out.
 - 10. The Triage Protocol must include an **individual dispute resolution process** to ensure fairness, accountability, and due process.
 - 11. The Triage Protocol must include a section dedicated to providing guidance and direction on the **duty to accommodate**.

ARCH's Recommendations are reproduced below following a discussion and rationale for each at the conclusion of each section.

I. Concerns with the overall Framework and Structure of the Triage Protocol

As noted at the July 15 Roundtable by members of the Bioethics Table, while it is not necessarily contemplated or envisioned that this Triage Protocol will be used beyond the COVID-19 pandemic, it will most likely inform responses to future pandemics.⁵ It is beyond

⁵ This point was succinctly made by Ms. Jennifer Gibson in her introduction providing background and context on the drafting of the Triage Protocol.

a doubt the Triage Protocol is an important document that will have long and consequential effects, some of which may be devastating and detrimental. Accordingly, it is imperative that such a document, despite its primary purpose being to provide direction to medical professionals, must not be framed solely within the medical model,⁶ but also within a human rights framework. This is to ensure that the benefits of any emergency response are also afforded to marginalized communities, rather than at their expense.

In its current version, the Triage Protocol lists a number of ethical principles to guide and inform allocation of scarce critical care resources. These principles are to be considered the starting point, the foundation of any decisions made about critical care in the context of a major surge of COVID-19. These guiding principles, accordingly, seep into and colour all aspects of decisions about scarce resources, which are admittedly difficult decisions with grave significance and great public importance. As such, it is imperative that the principles that guide these decisions are strong, principled, and align with a human rights framework.

In short, the framework within which this Triage Protocol is being drafted must be reformed and reshaped. Without this necessary reformation, discrimination will continue to plague the Triage Protocol. As such, it is recommended that in drafting the Triage Protocol, the authors view the issues from a human rights lens, and in particular from a disability rights and intersectionality lens.

The Right to be Free from Discrimination

The Triage Protocol must be guided by non-discrimination in its own right. The right to be free from discrimination is a quasi-constitutional right afforded to every Ontarian and Canadian,⁷ including when receiving health care services and medical attention.⁸ It is a right that is elevated above other legal rights and restrictions.⁹

4

⁶ Law Commission of Ontario, The Law As It Affects Persons With Disabilities. Preliminary Consultation Paper: Approaches to Defining Disability [2009], online: Law Commission of Ontario www.lco-cdo.org

⁷ Ont Human Rights Comm v Simpson-Sears, [1985] 2 SCR 536 ["Simpson-Sears"].

⁸ Eldridge v British Columbia (Attorney General), [1997] 3 SCR 624 ["Eldridge"].

⁹ Simpson-Sears, supra note 7.

A patient's right to be free from discrimination is not given its due weight in Triage Protocol 2. Guiding Principle 4, "Equity and Respect for Human Rights", where a mention of a patient's human rights is briefly made, is problematic for two reasons. First, it places the right to be free from discrimination on the same pedestal as other guiding principles, including beneficence and accountability. This is inappropriate, namely for the aforementioned reason that the right to be free from discrimination is a quasi-constitutional right, whereas beneficence, for example, is not. Second, Guiding Principle 4 is problematic because it collapses Equity and Human Rights and treats them as the same, or interchangeable, concepts which they are not.

Reframing the Triage Protocol 2 to reflect that the right to be free from discrimination is separate from, and superior to, the guiding principles will more accurately signal how fundamental and integral human rights law must be to the decision-making process. Moreover, this reframing will also account for, and acknowledge, intersectionality and how individuals who identify with multiple protected grounds by human rights law are impacted by the Triage Protocol.

Intersectionality¹⁰ is a term used to refer to instances where persons may experience discrimination on more than one human rights protected ground simultaneously. The importance of an intersectional lens has been emphasized by the Human Rights Tribunal of Ontario which has stated that an awareness of compound discrimination is necessary in order to avoid a narrow and one-dimensional perspective.¹¹

In the context of the Triage Protocol, it must be recognized that in treating patients who contract COVID-19 and require critical care within a surge, doctors must be cognizant of the compound discrimination that for example, a Black woman with a disability may experience. Accordingly, this section in the Triage Protocol should include a concrete explanation of what non-discrimination means and how it should be applied in a triage setting, such as

¹⁰ Professor Kimberlé Crenshaw introduced the term intersectionality in 1989 to address the marginalization of Black women within not only antidiscrimination law but also in feminist and antiracist theory and politics. The term was elaborated upon by Professor Crenshaw in 1991 and has been adopted by human rights law.

¹¹ Baylis-Flannery v. DeWilde (No. 2), (2003) 48 CHRR D/197 (Ont HRT) at para 144.

"disability, age, race, or any other protected ground cannot factor, even 1%, into triage decisions." ¹²

In sum, the Triage Protocol must be framed within a human rights approach and place the principle of non-discrimination at the forefront, in order to set the proper foundation for triage decisions regarding the allocation of scarce resources and to give effect to the quasi-constitutional status of these rights.

Medical Utility is not a Proper Guiding Principle

Medical utility as a guiding ethical principle in the Triage Protocol is problematic. As set out in Triage Protocol 2, medical utility strives to create the maximum good for the maximum number of people.¹³ While appearing facially neutral, utilitarianism actually often leads to adverse impacts for persons with disabilities.¹⁴ By virtue of this principle, those that are not able-bodied are less likely to be part of the group that receives the "good" in question.

Utilitarian frameworks do not consider existing systemic health disparities.¹⁵ Many persons with disabilities do not have equitable access to health care or health care outcomes. Many require additional resources to achieve equal health outcomes due to the need for disability-related accommodations, or due to systemic social inequities and/or intersectionality. But where a person's health outcomes may be influenced by these factors, utility has the unintended consequence of disregarding individual needs.¹⁶ A purely medical utility model

¹² AODA Alliance, A Discussion Paper on Ensuring that Medical Triage or Rationing of Health Care Services During the COVID-19 Crisis does not Discriminate Against Patients with Disabilities, April 14 2020, online: <a href="https://www.aodaalliance.org/whats-new/a-discussion-paper-on-ensuring-that-medical-triage-or-rationing-of-health-care-services-during-the-covid-19-crisis-does-not-discriminate-against-patients-with-disabilities/ ["AODA Alliance April Discussion Paper"]. See also, AODA Alliance, In a Second COVID-19 Wave, if there aren't enough Ventilators for all Patients Needing them, a new Draft Ontario Protocol Would Continue to Discriminate Against COVID-19 Patients with Disabilities, July 16 2020, online: https://www.aodaalliance.org/whats-new/in-a-second-covid-19-wave-if-there-arent-enough-ventilators-for-all-patients-needing-them-a-new-draft-ontario-medical-triage-protocol-would-continue-to-discriminate-against-covid-19patients-with-d/

¹³ Triage Protocol 2, supra note 1 at 2.

¹⁴ Şerife Tekin, Health Disparities in COVID-19 Triage Protocols, April 8, 2020, Impact Ethics, online: https://impactethics.ca/2020/04/08/health-disparities-in-covid-19-triage-protocols/

¹⁵ Tekin, *ibid*.

¹⁶ Tekin, *ibid*.

has been criticized as "ruthless" ¹⁷ and at odds with societal values of defending and advancing the rights of marginalized communities. ¹⁸

The problems with medical utility being a guiding factor are compounded when one considers that Triage Protocol 2 has attempted to distance itself from the pre-existing health and social inequities experienced by persons with disabilities and other marginalized groups in Ontario. At page 4 of Triage Protocol 2, it states that the pre-existing health and social inequities that have been revealed by the COVID pandemic will not be resolved by a triage approach.

Instead Triage Protocol 2 suggests that proactive measures must be taken in other sectors in order to prevent vulnerable groups from disproportionately contracting COVID. In effect, Triage Protocol 2 is offloading responsibility for these disproportionate impacts and distances itself from the systemic and pervasive barriers to health care in our society. This distancing is troubling, given that the very guiding principles that the triage approach is based on are likely to perpetuate and compound adverse health outcomes.

While the Triage Protocol cannot be expected to right all the systemic barriers experienced by marginalized communities, it cannot be permitted to perpetuate and compound these same inequities. Recognition of those pre-existing inequities is an important contextual factor that must be incorporated into and compensated for in the triage approach. This is an objective that is difficult to reconcile with pure medical utility being a primary guiding principle.

Focus on Impact

The Triage Protocol as a whole is written from a lens of intention without any focus on the impact that decisions made will have on patients from marginalized communities. It is well-established in human rights law that the intention to, or not to, discriminate is

¹⁷ See HHS Office for Civil Rights in Action, Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19), march 28, 2020, online: https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf . See also Peterson, Andrew, Emily A Largent, Emanuel Hart & Jason Karlawish, "Ethics of reallocating ventilators in the covid-19 pandemic" *BMJ* 2020;369:m1828, online: https://www.bmj.com/content/369/bmj.m1828

¹⁸ New York State Task Force on Life and the Law, New York State Department of Health, Ventilator Allocation Guidelines, November 2015 at 41, online:

https://www.health.ny.gov/regulations/task force/reports publications/docs/ventilator guidelines.pdf

inconsequential and not a governing factor in determining whether or not a person has experienced discrimination.¹⁹ Rather, it is the effect or impact experienced by the person alleging discrimination that is the focus of any human rights analysis.²⁰

It is clear that neither the first version of the Triage Protocol nor Triage Protocol 2 contemplate the adverse impact that will be experienced by persons from marginalized communities, including persons with disabilities, flowing from decisions made pursuant to said Protocol. The inclusion of guiding ethical principles like medical utility²¹ and (formalistic) fairness²² demonstrate that the Triage Protocol inappropriately emphasizes the doctor's intention, without turning its mind to the adverse impact that will be experienced by the person with a disability.²³ The result is a Triage Protocol with an approach that is problematic and discriminatory in nature.

Accordingly, a shift in the drafting framework must occur. The important question is not, whether the triage approach appears to be neutral and well-intentioned, but rather, whether marginalized communities could be adversely impacted. This shift in focus should lead to a shift in perspective when contemplating the guiding ethical principles; for example, when the focus is impact and not intention then substantive fairness, rather than formalistic fairness, becomes the objective.

Framework and Structural Recommendations:

- 1. Non-discrimination must be a guiding principle in its own right to ensure appropriate weight is given to human rights in triage decisions.
- 2. The Triage Protocol must not rely on medical utility as its primary guiding principle, as it leads to adverse consequences for persons with disabilities, and fails to consider systemic health discrepancies.

¹⁹ Simpson-Sears, supra note 7 at paras 12-13.

²⁰ *Ibid.*

²¹ Triage Protocol 2, *supra* note 1 at 2.

²² *Ibid* at 3.

²³ An apt example of this, of course, is the inclusion of the Clinical Frailty Scale in the Triage Protocol 2. This is further explored below.

3. The framework must shift from a focus on the intention not to discriminate to whether adverse impact (discrimination) flows from the approaches embodied in Triage Protocol 2.

II. Concerns regarding the process of Triage Protocol development

Follow-Up Communication to March Triage Protocol

It is imperative that Ontario Health notify the recipients of the first draft that it is not to be operationalized or applied.

In the cover letter to Triage Protocol 2, the Bioethics Table states that the March 28, 2020 Triage Protocol was sent out to hospitals by Ontario Health. In particular, it states that "[t]he draft recommendations were shared by Ontario Health with hospitals on March 28, 2020 to help hospitals prepare for the possibility of a major surge in critical care demand and to prevent catastrophic health outcomes as have been seen in other jurisdictions."²⁴

We are deeply concerned that, at the time it was delivered and distributed to hospitals and medical associations at least, it was not made clear to the recipients that these recommendations and the Triage Protocol in which they are housed were a draft.²⁵ The potential harm of this oversight cannot be overstated. Given the highly problematic and discriminatory nature of the first draft, the concern is that should hospitals hit surge prior to the approval or authorization of an improved version, then doctors will rely on the previous version, which may lead to devastating and disproportionate impacts on persons from marginalized communities.

Case in point: in or around May 2020 it was brought to ARCH's attention that at least three different medical organizations had published the draft Triage Protocol on their websites as a

²⁴ Correspondence from Ontario COVID-19 Bioethics Table to Roundtable Participants dated July 7, 2020 at

²⁵ This is the second time ARCH raises this concern. It was first raised in ARCH's May 13, 2020 submissions where we stated: A further concern is that, despite stating that the current version of the Triage Protocol is a draft, the Government has taken no action to clearly withdraw the draft to ensure that it is not implemented should the medical system become overburdened whilst Ontario Health conducts consultations. See ARCH May Submission, *supra* note 3.

resource for its members – including doctors, nurses and other health professionals – as if this was a finalized document.

Around the middle of May 2020, ARCH reached out to these three organizations, namely the Nurse Practitioners' Association of Ontario (NPAO), CorHealth Ontario, and Canadian Association of Emergency Physicians (CAEP), and requested that they immediately remove the draft Triage Protocol from their websites in light of the Provincial Government's statement that this was a draft and not a finalized document. Each organization complied.

It is beyond ARCH's reach, however, to contact every single hospital and medical association to which the Triage Protocol was delivered on March 28, 2020 or soon thereafter. Frankly, it is also beyond ARCH's responsibility to do same. Rather, it is incumbent upon Ontario Health to discharge this responsibility.

Accordingly, it is imperative that Ontario Health immediately contact every recipient of the original Triage Protocol to (a) ensure that the hospital/medical association is aware that the March 28, 2020 version is a draft that is not to be relied upon nor implemented, and (b) to ensure that no hospital staff or medical organization members are referring to or relying on that version of the Triage Protocol.

Clear and Plain Language Versions of the Triage Protocol

It is understood that the primary purpose of the Triage Protocol is to provide guidance to medical professionals and healthcare workers in the event that Ontario hits surge conditions. Simultaneously, however, it must be recognized that it is members of the public who will be subject to and impacted by decisions made pursuant to this Triage Protocol. Consequently, the public is entitled to know how doctors are expected to make these decisions and the basis upon which these decisions are made.

For clarification, clear language and plain language are two distinct concepts and are not to be used interchangeably. *Clear* language refers to the use of straightforward, direct language to convey ideas in a simple manner making the document accessible to everyone. *Plain* language is the use of techniques, like providing concrete examples and using clear language, to ensure that people with intellectual and/or developmental disabilities are able to access the information.

Accordingly, it is recommended that both clear language *and* plain language versions of the Triage Protocol be developed and made available to the public to disseminate this information in an accessible manner to as wide an audience as possible. It is imperative that *any* and *all* versions of the Triage Protocol be made accessible. This means that not only should the final version of the Triage Protocol also be produced in clear and plain language versions, but any drafts developed along the way as well.²⁶

Wider Consultations Needed

Wider consultations on a document such as Triage Protocol 2, which will have wide and varying effects, including consequences that may be detrimental in nature, is imperative. These consultations, however, cannot be formalistic nor performative.

Consultations are imperative in order to ensure that the perspectives of persons who are being disproportionately impacted by COVID-19 and who are, in turn, disproportionately impacted by the Triage Protocol are considered and incorporated. This, of course, includes the perspective of persons with disabilities, Indigenous persons and persons from racialized communities including Black persons and persons from other racialized communities. Moreover, wider consultations ensure that a multi-dimensional lens, including one that emphasizes intersectionality, is applied when drafting any Triage Protocol.

It is important to note, however, that in order to have these consultations be truly accessible and receive feedback from relevant stakeholders, including persons with disabilities, a clear language and plain language versions of the Triage Protocol must be made available to said stakeholders (as stated above). The absence of an accessible version dilutes the purpose of these consultations, namely, to receive feedback from persons from disability communities.

11

_

²⁶ At the July 15, 2020 Round-table discussion co-convened by the Bioethics Table and the Ontario Human Rights Commission, Ms. Jennifer Gibson clarified that she had been advised that there is currently a clear language version of the Triage Protocol being developed.

Process-related Recommendations:

- 4. Ontario Health must communicate to every hospital and medical association/organization that the Triage Protocol dated March 28, 2020 is not be relied upon or implemented.
- Clear language and plain language versions of all drafts and the final version of the Triage Protocol are to be produced and distributed widely so that all relevant stakeholders are able to understand the information and provide feedback.
- 6. Wider consultations are to be undertaken by the Bioethics Tables to ensure that the perspectives of persons with lived experience from marginalized and disproportionately impacted communities are heard and inform the drafting of the Triage Protocol.

III. Substantive Concerns regarding the Triage Protocol

The Continued Inclusion of the Clinical Frailty Scale

The Clinical Frailty Scale (CFS) must be entirely removed from Triage Protocol 2.²⁷ While Triage Protocol 2 removes the visual chart of the CFS, it is still referred to in the exclusion criteria chart²⁸, albeit more infrequently than in the previous draft, and is included in Appendix C as a Triage Criteria Tool.²⁹

As already submitted in ARCH's Brief dated May 13 2020, the CFS is included in the Triage Protocol to serve a purpose for which it was neither designed nor developed. The application of the CFS to persons with disabilities without the context of a pandemic is inappropriate. The application of the CFS to persons with disabilities within the context of a pandemic is catastrophic and devastating.

12

²⁷ These submissions are made in addition to ARCH's previous objections to the inclusion of the Clinical Frailty Scale. See ARCH May Submissions, *supra* note 3.

²⁸ Triage Protocol 2, *supra* note 1 at 7.

²⁹ *Ibid* at 20.

It is understood that the goal and intention of the CFS is to create a situation where all patients are treated fairly by applying the same metric across the board in a non-discriminatory manner,³⁰ this belief, however, is not only misguided, but a deductive and logical fallacy. In applying the CFS as it is, to all patients, the able-bodied will always score lower (for example, a 1 on the CFS) and persons with disabilities will always score higher deeming them frail.³¹ In a pandemic setting this means that the able-bodied person will always be prioritized for care over persons with disabilities. This is not fairness nor is it treatment on an equitable basis.

Several jurisdictions have already recognized the error in initially including the CFS in their Triage Protocols and have remedied their error by removing the CFS from any COVID-19 protocols and committing to an individualized assessment of each patient. For example, in the United Kingdom,³² the use of the CFS was challenged and the government conceded the problematic nature of the CFS for the purposes of allocating critical care resources.³³ Despite this, reliance on this problematic scale persists in Triage Protocol 2.

Recalling that intention is of no consequence – it is irrelevant whether, with the application of the CFS, a doctor, healthcare worker, hospital, medical organization or government department intended to discriminate against a specific demographic of patients or not. Rather, of importance is the adverse *impact* experienced by a person with a disability by being subject to a seemingly neutral metric that will disproportionately place them at a disadvantage

-

³⁰ Lastly, the July Triage Protocol provides an explanatory note following the exclusion criteria chart noting the purpose for which the CFS is to be used. This qualifier does provide some clarification; however, in saying that, the Bioethics Table still has not demonstrated why the inclusion of the CFS is of necessity in the first place. Secondly, the explanatory note focuses on the *intention* of the CFS rather than the *impact*.

³¹ A salient point here, of course, is that frailty and disability are two distinct issues — a distinction that the CFS

³¹ A salient point here, of course, is that frailty and disability are two distinct issues – a distinction that the CFS and the Triage Protocol both fail to acknowledge.

³² Hodge, Jones & Allen, News Release, *NICE Amends COVID-19 Critical Care Guideline After Judicial Review Challenge*, March 31, 2020 available: https://www.hja.net/press-releases/nice-amends-covid-19-critical-care-guideline-after-judicial-review-challenge/

³³ The Bioethics Table's attention is also directed to the states of Alabama, Tennessee and Washington in the United States for similar legal challenges to the identification of specific disabilities to be excluded or deprioritized from receiving critical care. Available: https://adap.ua.edu/uploads/5/7/8/9/57892141/al-ocr-complaint_3.24.20.pdf and http://thearc.org/wp-content/uploads/2020/03/2020-03-27-TN-OCR-Complaint-re-Healthcare-Rationing-Guidelines.pdf

The inclusion of the CFS in the Triage Protocol may not have been accompanied by an intention to discriminate, and yet the adverse impact experienced by persons with disabilities is real and tangible. In short, the adverse impact that flows from the inclusion and application of the Triage Protocol renders it discriminatory, regardless of the initial intention.

Survivability Beyond COVID-19

It is inappropriate to rely on ineligibility criteria that extends beyond the recovery of the acute COVID-related event.³⁴ It is arbitrary and invites a higher risk of ableist value assumptions about the quality of a person's life, which will inevitably cause a disproportionate adverse impact on persons with disabilities.³⁵

Triage Protocol 2 states that a person would be ineligible for critical care where they have a low probability of surviving "more than a few months" beyond recovering from COVID.

Triage Protocol 2 further explains that a person would be ineligible if they were "very likely to die in the near future if they recovered from their critical illness."³⁶

First, "more than a few months" is a speculative and subjective assessment, which could mean a number of different things to different doctors making these decisions. Second, this criteria goes beyond an assessment of the person's chance of survival of the acute COVID-19-related event, and invites ableist presumptions about chances of survival or quality of life

³⁴ A helpful and concrete example of this can be found in the AODA Alliance April Discussion Paper, supra note 12. The example is as follows:

A patient with a history of cancer contracts serious COVID-19 symptoms and goes to hospital for emergency treatment. They need a ventilator. The hospital has too few ventilators to meet the needs of all its COVID-19 patients who need ventilators.

A physician is considering which patients will get a ventilator. The physician decides that the cancer patient's long-term future lifespan may be shorter due to their cancer than other patients who have no disability. That physician thinks that this should be a factor weighing against that cancer patient getting the use of a ventilator. Such decisions should not be based on the physician's predictions, whether accurate or stereotype-based, about the eventual long-term lifespan of that patient unrelated to the COVID-19 diagnosis. The hospital or physician deciding who will get the ventilator must not weigh or hold against that patient with a disability the fact of their disability or its perceived impact on their long-term lifespan.

³⁵ Trudo Lemmens, Quebec's clinical triage protocol opens door to discrimination, June 15, 2020, online: https://policyoptions.irpp.org/magazines/june-2020/quebecs-clinical-triage-protocol-opens-door-to-discrimination/

³⁶ Triage Protocol 2, *supra* note 1 at 5.

after Intensive Care Unit (ICU) treatment to seep into clinical evaluations.³⁷ These types of assessments tend to disproportionately affect people with disabilities.³⁸

As stated by Profs. Trudo Lemmens and Roxanne Mykitiuk:

While the protocol does not clarify the time frame used to determine the risk of 'mortality' (i.e. mortality by when?), it goes beyond survival in the ICU, and includes the likelihood of survival months after ICU treatment. As mentioned above, the further one moves beyond ICU discharge, the more a policy will disproportionately impact on the elderly and people with disabilities.³⁹

It is clear that survivability beyond the acute COVID-related incident is subjective, arbitrary, and risks discriminating against persons with disabilities. As such, it must not be relied on as a criteria of ineligibility.

Random Selection

Safeguards must be put into place to ensure that random selection is not polluted by unconscious biases and prejudices. In an effort to uphold the principle of fairness, Triage Protocol 2 suggests applying the method of random selection in situations where it is not possible to rely on medical utility to make clinical decisions.⁴⁰ The aim, according to Triage Protocol 2, is to mitigate against the potential of explicit or unconscious bias in decision-making.⁴¹

The concern is how random selection will be carried out in practice as any decision-making is always subject to human and inherent bias. Triage Protocol 2 is vague as to how random

³⁷ Roxanne Mykitiuk & Trudo Lemmens, Assessing the value of a life: COVID-19 triage orders mustn't work against those with disabilities, April 9, 2020, CBC online: https://www.cbc.ca/news/opinion/opinion-disabled-covid-19-triage-orders-1.5532137;

³⁸ Trudo Lemmens & Roxanne Mykitiuk, "Disability Rights Concerns and Clinical Triage Protocol Development During the COVID-19 Pandemic" 2020 HLCJ 40:4 at 107.

³⁹ Lemmens & Mykitiuk, *ibid*.

⁴⁰ Triage Protocol 2, *supra* note 1 at 8.

⁴¹ Ibid.

selection will translate into practice, only noting that "a record of the outcome of the process of randomization should be documented."⁴²

In order to remedy against the influence of inherent bias, safeguards must be put in place to ensure a truly random selection process. It is also important to ensure that accountability and transparency are pillars in any random selection process implemented pursuant to the Triage Protocol. It is of utmost importance that the Triage Protocol be specific and thorough in how the random selection process is to be applied. As it stands at the moment, there is very little guidance and direction on this point which will lead to different practices of random selection across hospitals.⁴³

Dispute Resolution Mechanisms

It is imperative that Triage Protocol 2 includes a dispute resolution mechanism. An appeals procedure is an essential procedural aspect of due process, which cannot be set aside in pandemic conditions.

In addressing the possibility of a dispute resolution process for patients/families who disagree with the outcome of a triage decision, Triage Protocol 2 suggests that a formal appeal process "may not be feasible or appropriate." Instead, it offers to patients who have been subject to triage decisions that the hospital "[c]ommunicat[e] the rationale" to the patient/family and "respond [...] compassionately to patient or family concerns." It also suggests that it will conduct a retrospective, global review by monitoring triage data, and reviewing and revising the approach to ensure it is not leading to adverse consequences. With respect, while these elements are important parts of a triage approach, this is not an acceptable substitute for individual due process.

⁴² Ihid

⁴³ It was noted at the July 15 Round-table by Ms. Jennifer Gibson that the aim of the Triage Protocol is to ensure that the same treatment and approach are taken across all hospitals. With respect, random selection as it is currently set out in Triage Protocol 2 fails to satisfy this objective as it is too vague and lacks direction to hospitals and healthcare workers.

⁴⁴ Triage Protocol 2, supra note 1 at 12.

⁴⁵ Triage Protocol 2, *ibid*.

⁴⁶ Triage Protocol 2, *ibid*.

To the contrary, it is possible and necessary to include an individual dispute resolution mechanism in Triage Protocol 2. A real-time review of individual complaints is vital for ensuring that no individual has been treated unjustly by the decision-makers and so that a new decision can be implemented before irreparable harm is done. This would allow the patient or family member to seek a remedy before a potentially discriminatory and irreversible decision is carried out.

Other jurisdictions recognize the importance of an appeal framework within a triage approach.⁴⁷ The University of Virginia Health System Ethics Committee, for example, recommends that triage decisions be supported by an appeal process in order "[t]o promote the ethical principles of trustworthiness, equity, fairness, and justice."

It has been noted that while global review of the triage approach is important for accountability and on-going improvement of the triage process, it "does not protect vulnerable patients, because it does not allow for timely intervention in individual triage decisions."⁴⁹ As the Indiana State Department of Health noted in its Crisis Standards of Patient Care Guidance, "while meticulous record keeping is desirable, in such cases, it is ethically important to prioritize energies spent in the direct saving of lives over those spent keeping records and in post-hoc analyses."⁵⁰

Duty to Accommodate

It is imperative that Triage Protocol 2 includes a section that focuses on providing specific guidance and directions about the duty to accommodate. Triage Protocol 2 makes only brief references to the provision of accommodations for persons with disabilities accessing the

⁴⁷ University of Virginia Health System Ethics Committee, "Ethical Framework and Recommendations for COVID-19 Resources Allocation When Scarcity is Anticipated" March 26, 2020 online: https://med.virginia.edu/biomedical-ethics/wp-content/uploads/sites/129/2020/03/Ethical-Framework-for-Co-vid-19-Resources-Allocation-3.26.20.pdf

⁴⁸ *Ibid* at 7

⁴⁹ Ibid at 233.

⁵⁰ Indiana State Dep't of Health, Crisis Standards of Care Community Advisory Group, Crisis Standards of Patient Care Guidance with an Emphasis on Pandemic Influenza: Triage and Ventilator Allocation Guidelines, 13 (2014) http://www.phe.gov/coi/Documents/Indiana%20Crisis%20Standards%20of%20Care%202014.pdf

Triage Protocol and decisions about critical care resources. These references are not specific nor directive.⁵¹

Disability-related accommodations for the purposes of accessing health care services are a basic tenet of human rights law.⁵² Disability-related accommodations ensure that persons with disabilities have equal opportunity to receive, understand, and benefit from critical care.

Other jurisdictions have acknowledged the importance of providing disability-related accommodations to persons to ensure they have equal access to health care during the COVID-19 pandemic. The British Medical Association's guidance for COVID-19 reiterates that hospitals have a positive obligation to ensure that persons with disabilities are able to access and take advantage of public services in a manner as closely as reasonably possible to someone without disabilities.⁵³ Similar directives can be found in other ICU decision-making guidance in jurisdictions like Tennessee.⁵⁴

Accommodations may include interpretation, alternative and augmentative communication, support persons, or other supports that allow a person to gain equal access to medical services.⁵⁵ These must be provided to the patient during the application of the Triage Protocol and the duration of the patient's time at the hospital.

⁵¹ Triage Protocol 2, *supra* note 1 at 3, 4 and 11.

⁵² Eldridge, supra note 8.

⁵³ British Medical Association, "COVID-19 – ethical issues. A guidance note" (2020) at 7, online (pdf): *BMA* https://www.bma.org.uk/media/2360/bma-covid-19-ethics-guidance-april-2020.pdf.

⁵⁴ Tennessee, Tennessee Altered Standards of Care Workgroup, *Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee (Version 1.6)* (2020) online: Tennessee State Government https://www.tn.gov/content/dam/tn/health/documents/cedep/ep/Guidance for the Ethical Allocation of Scarce Resources.pdf .

⁵⁵ See AODA Alliance April Discussion Paper, *supra* note 12:

More than one hospital patient needs a ventilator. There are not enough ventilators for all the patients who need one at that hospital. At least one of the patients who needs a ventilator has disabilities. Some of the patients who need a ventilator have no apparent disabilities.

One of the patients with disabilities who needs the ventilator will need disability-related accommodations in hospital in order to receive health care services, such as a deaf patient who needs Sign Language interpreters to effectively communicate with hospital staff. The emergency room doctor, deciding who will get the ventilator, is concerned that the patient with disabilities who needs such accommodations in the hospital setting will pose a greater demand on the hospital's services and resources, if they survive, than would other patients who need the ventilator.

Triage Protocol 2 should include detailed directives regarding how accommodations are provided in the context of a pandemic. Disability-related needs vary depending on the person with a disability and may fluctuate throughout a period of time. Accordingly, and as discussed in the preceding paragraph, it is highly recommended that best practices be included such as asking each patient in the emergency room and/or upon admission to the hospital if they require disability-related accommodation and, if they do, what those accommodations are. These patient-specific accommodations should be recorded in the chart and applied by every healthcare worker that comes into contact with the patient. Practices such as these that are in line with human rights obligations will also assist in ensuring that all appropriate accommodations are in place when any assessments are made pursuant to the Triage Protocol.

Substantive Recommendations:

- 7. The Triage Protocol must not rely on the Clinical Frailty Scale in any capacity.
- 8. The Triage Protocol must eliminate eligibility criteria that considers survivability beyond the acute COVID related event.
- 9. Triage Protocol 2 should provide clear and specific guidance and direction as to how random selection should be carried out.
- 10. The Triage Protocol must include an individual dispute resolution process to ensure fairness, accountability, and due process.
- 11. The Triage Protocol must include a section dedicated to providing guidance and direction on the duty to accommodate.

Conclusion:

In sum, there continue to be concerns with Triage Protocol 2 that must be rectified to ensure that any response to a surge in COVID-19 cases does not adversely and disproportionately impact persons from marginalized communities including but not limited to persons from disability communities, elderly persons, Indigenous persons, Black persons and persons from other racialized communities.

The hospital or physician who is deciding who will get to use the ventilator must never use a patient's need for disability-related accommodations as a factor or reason for refusing them the ventilator.

The above submissions address a number of those concerns and provide Recommendations for reform. The Recommendations herein aim to align the Triage Protocol with human rights law and ensure that marginalized communities are not disproportionately impacted. The Recommendations impact the overall structure and guiding principles of the document, those related to the process within which the Triage Protocol has been developed, and those related to the substantive concerns, such as the use of the Clinical Frailty Scale or survivability beyond the acute event as metrics to assess patients, the use of random selection, the lack of a dispute resolution mechanism, and the importance of upholding the duty to accommodate.

Please do not hesitate to contact us should you wish to discuss any of these Recommendations in further and greater detail.

Sincerely,

ARCH DISABILITY LAW CENTRE

Robert Lattanzio

Executive Director

Mariam Shanouda Staff Lawyer

Jessica De Marinis Staff Lawyer