COVID-19 Guidance: Clinical Advice

9 April 2020

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Introduction

The Commission welcomes the opportunity to be able to comment on the *COVID-19 Guidance: Clinical Advice* in appreciation of the fact that it has been produced rapidly and continues to evolve. During the passage of COVID-19 emergency legislation we called for "an ethical framework for both health and social care in Scotland which sets out ethical and human rights-based principles to guide decision-making"[1]. We believe that the guidance would be significantly enhanced by explicit consideration of and reference to human rights standards and principles, which legally underpin the duties on those on the frontline tasked with making difficult decisions at this time.

[1] http://www.scottishhumanrights.com/media/2003/briefing-covid-19-emergency-legislation-scotland-vfinal.docx

Issues and Recommendations

We are aware of a number of concerns raised by disabled people, older people and the organisations which represent them, some of which were prompted by the Critical Care guidance[2] released by NICE for England and Wales on 20 March (which we understand has subsequently been updated). Those concerns, exacerbated by stories reported in the media, include blanket non-treatment policies being applied to care home residents, and Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) notices being encouraged for those with long term conditions without full discussion between doctors, their patients and carers or appropriate processes. While the primary audience of the guidance may be medical professionals, we consider that it plays an important public information role in clarifying concerns and reassuring sectors of the population concerned about how they will be affected. It is therefore crucial that the guidance is amended and presented in a manner accessible to the general public.

In recognition both of its impact on disabled people and the general obligations of the UN Convention on the Rights of Persons with Disabilities (CRPD) to involve disabled people in decisions concerning their human rights (Article 4), we recommend that disabled people's organisations[3] are brought in to work collaboratively on the guidance as it is amended.

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[2] *COVID-19 rapid guideline: critical care in adults*
https://www.nice.org.uk/guidance/ng159

[3] Defined as organisations "led, directed and governed by persons with disabilities" per General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention, UN Committee on the Rights of Persons with Disabilities

Clinical decision-making engages a range of human rights and, importantly, can be informed and supported by explicit inclusion of human rights standards in guidance being employed on the frontline. The European Convention on Human Rights (ECHR) provides legal underpinning through the Human Rights Act 1998 and important duties also arise from the UN Convention on the Rights of Persons with Disabilities. Fundamentally, CRPD is grounded in the social model of disability which requires respect for difference and acceptance of persons with disabilities as part of human diversity and humanity, and recognition and removal of the barriers which serve to disable people.

In this context, particular attention should be paid to:

- The right to life (Article 2 ECHR)
- The right to non-discrimination on grounds such as age and disability (Article 14 ECHR and reflected across UN human rights treaties including the CRPD
- The right to autonomy and participation in decision-making (Article 8 ECHR and Article 12 CRPD), which requires not just informed choice but also support for decision-making where a person may have additional needs.
- The concept of qualified rights, which necessitates that any restrictions on rights such as the right to private and family life must be lawful, necessary, proportionate and non-discriminatory. This provides a clear presumption against blanket decision-making
- The right to equal treatment in situations of risk and humanitarian emergencies (Article 11 CRPD)

We believe that the guidance would benefit from an explicit statement of the requirements of these rights in application to clinical decision-

making. A statement like NHS England and NHS Improvement's communication captures much of these principles[4]:

> "*We should be cognisant of the principle of equity of access for those who could benefit from treatment escalation, and the principle of support for autonomy for those who want to be involved in decisions.*"

Human rights standards should also be reflected in key areas by stating what is **not** permissible, even though this may appear obvious to clinicians. It is not clear that such standards are currently being breached, however, it is vital that they are explicitly set out in clinical guidance:

- The requirement not to apply blanket policies in areas such as anticipatory care planning and DNACPR decisions. DNACPR orders can be an appropriate and respectful way to facilitate a person's autonomy in decisions about their end of life care, where they are supported to exercise their capacity to make an informed choice.
- Basing decisions to refuse access to critical care on the basis of age or mental or physical disability which is not clinically relevant to the prospect of survival
- Making assumptions about quality of life, which is set out clearly in the *Covid 19 and the rights of disabled people* statement by disabled people's organisations [5]. In this regard, the "acceptable

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[4] *Maintaining standards and quality of care in pressurised circumstances* https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/maintaining-standards-quality-of-care-pressurised-circumstances-7-april-2020.pdf

[5] *Covid 19 and the rights of disabled people – statement supported by disabled people's organisations and allies*

quality of life" referred to at p.13 should be amended to reflect that this must be determined by reference to the individual's own views and their known or ascertainable wishes and feelings.

Napier University's Centre for Mental Health and Capacity Law has provided detailed commentary on how legal, ethical and human rights requirements would improve the guidance[6]. We support that analysis and suggest that their specific recommendations for amendments would provide a stronger human rights foundation to the guidance.

We wish therefore to highlight the following key messages:

- The guidance recommends that the Clinical Frailty Scale (CFS) be used as a basis for general assessment and that a score of 5 is "good evidence regarding the expected benefit of critical care organ support". While the document states (at p.9) that clinicians should have awareness of its limitations, we believe that the limitations need to be set out in detail and addressed here. In particular, they must address the potential for inappropriate use in particular groups for whom the CFS has not been validated (anyone under 65, those with learning disabilities or autism), its potential for misapplication in those with stable long-term conditions and that it is only part of shared decision-making along with the patient. For example, the Specialised Clinical Frailty Network's description of the CFS is much clearer on these points and similar content ought to be reflected here.

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https://www.disabilityrightsuk.org/news/2020/april/covid-19-and-rights-disabled-people

[6] *Comment on Scottish Government Chief Medical Officer's (1) COVID-19 Guidance: Clinical advice version 2:3 (3rd April 2020); and (2) COVID-19 Guidance: Ethical Advice and Support Framework version 2:2 (3rd April 2020)* http://blogs.napier.ac.uk/cmhcl-mhts/2020/04/08/comment-on-cmo-covid-19-guidance-clinical-advice-version-23-3rd-april-2020/

*"**Please note:** **The CFS has not been widely validated in younger populations (below 65 years of age), or in those with learning disability. It may not perform as well in people with stable long term disability such as cerebral palsy, whose outcomes might be very different compared to older people with progressive disability. We would advise that the scale is not used in these groups. However, the guidance on holistic assessment to determine the likely risks and benefits of critical care support, and seeking critical care advice where there is uncertainty, is still relevant.**"*[7]

Making these aspects clear would enhance the principles of proportionality, participation in decision-making and non-discrimination.

- The requirement for support for decision-making arises specifically in relation to people whose mental or physical disability means they require such support but we recognise that many more people may have difficulty understanding their options at times of crisis and may require additional support. We believe that staff should be provided with clear decision-making tools to support them in having these conversations and support the commentary by the Centre for Mental Health and Capacity Law on improvements required to Appendix 2, Anticipatory Care Planning, in this regard.

- Appendix 3 lists, among factors to be considered, "age", "nursing home resident" and being "dependent on ADLs". We are extremely concerned that this list tends towards blanket application of decisions towards certain groups and may be discriminatory. At the very least, it may give this impression to those within those

[7] https://www.scfn.org.uk/clinical-frailty-scale

groups. We take ADLs to mean "activities of daily living", however, this is one of a range of technical terms and acronyms used within the document that would benefit from clarification if the guidance is to perform a public information role.

Our comments in relation to the Clinical Guidance highlight that there are a range of human rights principles and standards that can and should be used to inform decision-making in this area. Accordingly, we believe the same approach needs to be taken to the Ethical Advice and Support Framework[8], the principles set out therein and the work of the Ethical Advice and Support Groups.

[8] https://www.gov.scot/publications/coronavirus-covid-19-ethical-advice-and-support-framework/