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Scottish mental health and capacity law: The normal, pandemic and ‘new normal’

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ABSTRACT

A state’s real commitment to its international human rights obligations is never more challenged than when it faces emergency situations. Addressing actual and potential resourcing pressures arising from the COVID-19 pandemic has resulted in, amongst other things, modifications to Scottish mental health and capacity law and the issuing of new guidance relating to associated practice. Whether these emergency or ordinary measures are invoked during the crisis there are potential implications for the rights of persons with mental illness, learning disability and dementia notably those relating to individual autonomy and dignity. This article will consider areas of particular concern but how strict adherence to the legal, ethical and human rights framework in Scotland will help to reduce the risk of adverse consequences.

1. Introduction

International human rights treaties identify minimum acceptable standards for the treatment and respect of individuals at all times. There is no greater indication of a state’s commitment to maintaining these than when it is faced with crisis situations.

In common with other jurisdictions, Scotland has been addressing the impact of the coronavirus crisis using a combination of ordinary and emergency legislation, other measures and guidance. Whichever of these is adopted, however, has definite implications for persons with mental illness, learning disability and dementia (persons with mental disorder)1 who may or may not have mental capacity issues.

With this in mind, this article will consider the principles of the Mental Health (Care and Treatment) (Scotland) Act 2003 (the MHA) and the Adults with Incapacity (Scotland) Act 2000 (AWIA) and outline the modifications that the UK Coronavirus Act 2020 and the Coronavirus (Scotland) Act 2020 have made to these Acts, most of which modifications have not yet been brought into force. It will also consider Scottish Government ethical and clinical guidance addressing wider treatment issues potentially affecting persons with mental disorder during the pandemic which, unlike the legislative modifications, are already operational although it is likely that certain aspects of these were intended to apply to substantial surges in infection and later planning.2 In each case, such consideration will involve discussion of legal, human rights, ethical and practical implications of using the ordinary or emergency legislative measures and the guidance both during and following the immediate COVID-19 crisis. In doing so it recognises the extreme pressures that health and social care services, the courts and the Mental Health Tribunal for Scotland, along with other public, private and voluntary bodies, are and are likely to continue to be under. However, at the same time it will identify areas of particular concern in terms of ensuring adequacy of care and treatment and respect for individual autonomy and dignity and how the human and equality rights framework in Scotland, if adhered to sufficiently, has the potential to ameliorate such concerns.

2. Emergency provisions and Scottish mental health and capacity law

As a devolved region of the UK, mental health and capacity law and health and social care fall within the legislative and policy competence of the Scottish Government and Scottish Parliament. However, emergency powers - such as those relating to a pandemic - are reserved to the UK Parliament3 although how and when these powers are implemented...
lies within the discretion of the Scottish Parliament and Ministers to the extent of their devolved powers. The UK Coronavirus Act 2020 was enacted on 25th March 2020 and makes several temporary modifications to Scotland’s MHA.10 Whilst the measures will only come into force if triggered by regulations they will, if and when in force, have serious implications for the liberty and autonomy of persons with mental disorder. The Coronavirus (Scotland) Act 2020 was subsequently enacted by the Scottish Parliament on 6th April 2020 which contained further modifications this time relating to the AWIA.6

Whilst most of the emergency legislative provisions have not yet come into force and, indeed, may never do so, they raise potential practical, ethical and human rights issues. An awareness and preparedness for these is thus essential.

2.1. Mental health legislation modifications

The MHA modifications introduced by the Coronavirus Act 2020 include:

a) Time extensions for Emergency Detention from 72 to 120 hours, Nurse’s Holding Power from 3 to 6 hours and open-ended time-scales for transferring prisoners to hospital.8

b) Reduced compulsion authorisation and review requirements such as permitting:

a. Approved Medical Practitioners to authorise and extend Short Term Detention Certificates without the usual requirement to consult with or obtain the consent of a Mental Health Officer
b. Mental Health Officers to apply for Compulsory Treatment Orders (CTOs) with the support of only one Approved Medical Practitioner report.9

c. The non-consensual administration of long-term medication before the usual second opinion certification from a Designated Medical Practitioner (DMP) has been received (but only if the DMP has not refused the certification).10

d. Suspending the requirement that Responsible Medical Officers review CTOs, Compulsion Orders, Compulsion and Restriction Orders (COROs) and Hospital Directions (HDS) and Transfer for Treatment Directions (TTDs) and that the Mental Health Tribunal for Scotland reviews COROS and HDS and TTDs.11 Although it is unclear how this will operate in practice the suspension of review would appear to allow for the continued detention and restriction of patients without an examination for possibly extended periods of time.

e. For Mental Health Tribunal panels to be reduced.12

Each of these modifications have potential implications for patients’ rights to liberty and autonomy more widely and, in the case of the Mental Health Tribunal panel changes, the right to a fair trial, or due process.

Similarly, the issue of individual rights to liberty and autonomy arises in connection with the Coronavirus (Scotland) Act 2020 modifications of the AWIA in that the ‘clock is stopped’ on time limits on guardianship orders and certificates authorising medical treatment.13

Further concern arises in connection with the modified section 13ZA Social Work (Scotland) Act 1968 (SWSA) provision that allows local authorities to move an adult who lacks capacity to a care setting.14 Normally local authorities must adhere to the AWIA principle that account be taken of the adult’s present and past ascertainable wishes and feelings and the views of guardians, attorneys, named persons and primary carers15 when making decisions about such a move, and the use of section 13ZA is expressly ruled out if a welfare guardian is in place or in the process of being appointed. Presumably with a view to, if necessary, making such transfers easier during the pandemic the Coronavirus (Scotland) Act 202016 removes the requirement to take account of the views of the adult and others, and permits section 13ZA to be used even if a guardian has been appointed who could legally authorise the placement. It therefore allows a move to take place without taking the adult’s or specified others’ views into account and even against their wishes. Anxiety has already existed over the use of this local authority power, given the possibility that it can be used to move a person who lacks capacity to a setting where they are deprived of their liberty but without any accompanying Article 5 European Convention on Human Rights (ECHR) safeguards, notably the ability to apply to a court to challenge or authorise the legality of such deprivation of liberty.17 The recent modification allowing local authorities to ignore the person’s views not only reinforces this but also calls into question whether it is legitimate to disregard an individual’s rights to respect for private and family life and exercise of legal capacity to this extent.18

2.2. Capacity legislation modifications

The focus of this article is upon COVID-19-related modifications to Scottish mental and capacity law and corresponding guidance. It is, however, worth noting that in terms of the adequacy of support in the community, emergency measures that are already in force relating to social care assessments raise issues in relation to the rights to the highest attainable standard of physical and mental health, to autonomy, dignity and independent living.20 The UK Coronavirus Act removes the statutory duty on local authorities in Scotland to assess social care needs where it would be impractical to do this or where to do so would cause unnecessary delay in providing community care services to an individual.21

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13 Section 4 and Schedule 3, paras 11(2)–(3) Coronavirus (Scotland) Act 2020 modifying sections 47, 58-58A and 60 AWIA.
14 Section 13ZA SWSA.
15 Section 1(4) AWIA.
16 Schedule 3, para 11(1).
17 Scottish Government Guidance for local authorities: provision of community care services to adults with incapacity CCD5/2007, 30 March 2007. Available at: https://www.sehd.scot.nhs.uk/publications/CC2007_05.pdf; Mental Welfare Commission for Scotland Mental Welfare Commission response to queries related to when to use s13ZA v Guardianship following the Cheshire West Supreme Court decision 17 September 2014. Available at: https://www.mwcscot.org.uk/sites/default/files/2019-07/cheshire_west_draft_guidance.pdf
18 Article 8 ECHR; Article 12 CRPD.
19 Section 87(2)(e) Coronavirus Act 2020.
20 See, for example, Health and Social Care Alliance Scotland, Social Care Assessment COVID-19 Human Rights Concerns. Available at: https://www.alliance-scotland.org.uk/blog/news/social-care-assessment-covid-19-human-rights-concerns/
21 Section 16 Coronavirus Act 2020.
3. The human rights framework in Scotland

The emergency modifications to the MHA, AWIA, SWSA and social care assessment obligations introduced by the Coronavirus Act and Coronavirus (Scotland) Act temporarily reduce certain procedural safeguards. However, with the exception of the relaxing of the need to take into account the adult’s and others’ views in relation to local placements, the requirement to take into account the MHA and AWIA human rights-based principles remains firmly intact.

The ordinary legislative requirement to rigorously ensure that the individual is ‘incapable’ in the case of the AWIA or, in the case of the MHA, has a mental disorder which causes ‘significantly impaired decision-making ability’ regarding treatment for such mental disorder before non-consensual interventions are considered is unaltered. The non-emergency requirements to adopt the least restrictive alternative in the circumstances, only intervene where benefit will be derived for the individual not otherwise achievable and take the individual’s wishes and feelings into account when determining and implementing any non-consensual intervention under either Act must still be adhered to. The MHA also highlights the importance of a patient participating in decisions about their treatment and being actively supported to do so, whilst the AWIA contains an ongoing requirement to support and encourage the decision-making ability of incapable adults.

The MHA and AWIA principles were primarily informed by the ECHR. The ECHR is embedded in the UK (including Scottish) legal framework by the Human Rights Act 1998 requiring public authorities to give effect to its rights and allowing for such rights to be enforced through national courts and tribunals. The ECHR purchase is even greater in Scotland where non-compliant devolved legislation and policy is unlawful and thus unenforceable.

Other international human rights treaties, however, also inform the implementation of existing Scottish mental health and capacity law, policy and practice despite the rights identified in these not being directly legally enforceable in Scotland. Importantly, the influence of these treaties not only situates persons with mental disorder within the mainly civil rights framework identified in ECHR but extends this to include their social, economic and cultural rights. This allows for the rights of individuals to be considered in their wider health and social care and societal context. Such treaties notably include the Convention on the Rights of Persons with Disabilities (CRPD) which the UK ratified after enactment of the MHA and AWIA, and also the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and its Optional Protocol, the International Covenant on Economic, Social and Cultural Rights, and the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment. The UK’s international legal duties as a state party to these treaties is reinforced in Scotland in that the UK Government can prevent proposed devolved legislation and policy which will result in a breach of the UK’s international obligations. Moreover, ECHR jurisprudence, which must be given effect in Scotland, should follow United Nations human rights treaties as a higher source of international law. The fact that the CRPD is recognised as being particular relevance to persons with mental disorder is reflected by the Scottish Government’s CRPD delivery plan A Fairer Scotland for Disabled People and Mental Health Strategy 2017–2027.

The emergency legislative modifications have been designed to address potential staffing and other resourcing challenges resulting from the pandemic and to ease processes to allow, where necessary, for individuals’ health and social care needs to be properly met. However, whether these or ordinary legislative measures are used during the COVID-19 crisis, several considerations arise and these will now be discussed.

4. Discussion

Coping with the COVID-19 pandemic may result in unprecedented demands being made on health and social care services, and measures have been proposed or adopted to address this. Whilst such measures may impact on the extent to persons with mental disabilities, and others, may enjoy the protections that such rights provide, these protections cannot be completely, disproportionally and discriminatorily reduced.

The state has an obligation to protect life and to take all necessary measures to ensure the protection and safety of persons with disabilities in emergency situations. At the same time, however, the state must guarantee individual rights to liberty, autonomy, dignity and the highest attainable standard of physical and mental health on an equal basis for all. Any limitation of such rights must have a legal basis and be necessary, proportionate and non-discriminatory.

The ECHR recognises that crises may exist where it might be appropriate to reduce human rights safeguards. However, state discretion, or the margin of appreciation, afforded to states to determine when an emergency threatening the life of the nation exists and which measures to take is not completely beyond the supervision of the European Court of Human Rights. States do not therefore have an entirely free rein in these circumstances.

In common with other human rights treaties, the ECHR is clear that the rights to life or to be free from torture and inhuman or degrading treatment are always absolute and untouched even in emergencies. Moreover, the UK Coronavirus Act 2020 and Coronavirus (Scotland) Act 2020 modifications may potentially limit the rights of persons with mental disabilities to liberty, to a fair trial and to respect for private and family life (or individual autonomy) but may only do so ‘...to the extent strictly required by the exigencies of the situation, provided that such measures are not inconsistent with its other obligations under international law.’ Proportionality and non-discrimination remain integral to the lawfulness of decisions about whether or not to use the ordinary provisions of the MHA, AWIA and SWSA or the emergency measures and the extent to which such provisions or measures can be interpreted as legitimately limiting rights. Considerations include whether the ordinary MHA, AWIA and SWSA provisions affording greater safeguards, rather than the emergency measures, would sufficiently achieve the intended purposes and how long an emergency measure remains in place and opportunities for review.

28 Article 2 ECHR; Article 11 CRPD.
29 Articles 5, 8, 3 and 14 ECHR; Articles 5, 12, 14, 15, 17, 19 and 25 CRPD.
30 This includes emergency measures. See Altan v. Turkey/Alpay v. Turkey (Apps Nos 13,237/17 and 16,538/17) Judgments of 20 March 2018, paras 119 and 183.
31 Article 15(1) ECHR.
32 Ireland v. United Kingdom (App No 5310/71) (1978) ECHR 1, para 207.
33 Brannigan and McBride v United Kingdom (1993) 17 EHRR 539, para 43. See also Altan v Turkey/Alpay v Turkey, paras 91 and 75.
34 Article 15(2) ECHR.
35 Article 5 ECHR.
36 Article 6 ECHR.
37 Article 8 ECHR.
38 Lawless v. Ireland (no. 3), paras 36 and 38; Ireland v. the United Kingdom, para 212.
39 Brannigan and McBride v. the United Kingdom, para 54; Ireland v. the United Kingdom, para 220.
the lawfulness of the use of the emergency provisions are also highly pertinent. Other factors such as causing minimum disruption to individual rights and whether there has been any consideration given to alternatives to involuntary detention are also pertinent. To this end both the UK and Scottish governments confirmed when introducing the Coronavirus and Coronavirus (Scotland) Bills that the measure would only be invoked if absolutely necessary and both resultant Acts contain sunset and review clauses.

As the MHA and AWIA modifications relate only to processes and they, and the extent of the pandemic, do not alter the requirement to apply existing criteria for non-consensual interventions and nor must the legislation be used for purposes for which it is not intended. For example, Article 5(1)(e) ECHR might allow for the detention of persons ‘prevention of the spreading of infectious diseases’ but this does not justify using the compulsion provisions of the MHA to authorise treatment and restrictions related to COVID-19 and separate legislative provision would be required as a legal basis. The lawfulness of decisions made under the MHA and AWIA, including those relating to the deprivation of liberty, can still be tested by application to the Mental Health Tribunal or the Sheriff Court (as appropriate). How effective this will be in the circumstances remains to be seen. Not all persons with mental disabilities will be in a position easily to initiate such a process and there are reports of a lack of accessibility to the courts during the COVID-19 crisis However, when the emergency measures cease to have effect and ordinary legislative review processes resume Articles 5, 6 and 8 ECHR issues will inevitably arise in that this will take time, and there may be questions surrounding the legality and proportionality of the suspension of regular statutory reviews, continued deprivation of liberty and restrictions on autonomy by non-consensual care, treatment and other interventions.

In addition, Article 5 and 8 ECHR concerns arise in connection with persons who lack capacity that have been moved to a care setting under the modified SWSA measures. This category of persons may find themselves deprived not only of their liberty but also automatic judicial review of its lawfulness both during and after the operation of the emergency measures.

Non-discrimination is an essential component of proportionality when considering the use of both ordinary legislation and emergency measures. The ECHR right to non-discrimination on the basis of a particular characteristic, which includes disability, must be strenuously read in conjunction with other ECHR rights. This applies equally to the state’s positive obligations to protect, for example, the right to life or respect for private and family life.

Article 15(2) ECHR, as already stated, requires that emergency measures are ‘…not inconsistent with its other obligations under international law.’ This would therefore include the CRPD which both reinforces and expands the ECHR non-discrimination message. The CRPD’s Committee on the Rights of Persons with Disabilities’ condemnation of restrictions of liberty and autonomy premised on the existence of mental disability and related impairment is a manifestation of the overall CRPD message that the existence of a mental disability or related impairment must never justify a lower level of rights enjoyment. Moreover, the CRPD extends this message to the enjoyment of the full range of civil, political, economic, social and cultural rights. In order to overcome inequalities in rights enjoyment it highlights the need to proactively support persons with disabilities to achieve this through, for example, supported decision-making, reasonable accommodation and universal design.

Clearly, the importance of providing access to appropriate supported decision-making, or support for the exercise of legal capacity, to actively support persons with mental disabilities to make their voice heard in health and welfare decisions on an equal basis with others cannot be underestimated. Such support may, of course, take many different forms but may include advance planning. It may also be found in peer, family or professional support, independent advocacy clearly and appropriately communicated information and, of course, in welfare powers of attorney and other forms of advance planning. Anticipatory care planning, as a means of such advance planning, will be discussed in more detail below. However, at this juncture it is worth noting that the objective of such support is to ensure that any difficulties with decision-making and expressing one’s views as a consequence of mental disorder are overcome in order to effect is given to the individual’s rights, will and preferences in the (footnote continued)

273–301. See A and others v United Kingdom (App No 3455/05) (2009) ECHR 301, para 190, where the European Court of Human Rights made it clear that unjustifiable discrimination impacts on the proportionality of emergency measures.

46 ECHR rights must be read in Article 14 ECHR.

47 Akandji-Kombe, J-F, Council of Europe, Positive obligations under the European Convention on Human Rights: A guide to the implementation of the European Convention on Human Rights, January 2007, Human rights handbooks, No. 7, Council of Europe. Available at: https://rm.coe.int/168007ff4d

48 Lawless v Ireland (no 3) (App no 332/57) (1961) ECHR 2, para 40; Brannigan and McBride v United Kingdom, paras 67–73.

49 Committee on the Rights of Persons with Disabilities (1) General Comment No 1 (2014): Article 12 Equal Recognition before the Law CRPD/C/GC/1, 19 May 2014; and (2) Guidelines on the right to liberty and security of persons with disabilities, Annex, Report of Committee on the Rights of Persons with Disabilities, General Assembly Official Records Seventy-second Session Supplement No 55 (A/72/55) 2017.

50 Article 5 CRPD; Committee on the Rights of Persons with Disabilities General Comment No 6 (2018) on Equality and Non-Discrimination CRPD/C/GC/6 28 April 2018.

51 Articles 12 (supported decision-making), 2, 5(3), 14(2), 24(2) (c), 24(5) and 27(1)(i) (reasonable accommodation and 2 and 4(1)(f) CRPD (universal design). See also Committee on the Rights of Persons with Disabilities (1) General Comment No 1 (2014) (op cit); (2) General Comment No 5 (2017) on living independently and being included in the community CRPD/C/GC/5 27 October 2017; and (3) General Comment No 6 (2018) (ibid).

52 United Nations Committee on the Rights of Persons with Disabilities (Chair), on behalf of the 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. Available at: https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25765&LangID=E
same way and to the same extent as others. 53

One modest and welcome change has been introduced in a second piece of Scottish emergency legislation which removes the requirement for a nominated Named Person under the MHA to sign a document before a witness accepting the nomination. 54

4.1. Wider treatment issues – ethical and clinical guidance

Alongside emergency legislation, the Scottish Government has issued a wide range of guidance 55 to support clinicians and other professionals in responding to the pandemic. This guidance has been developed and issued at great speed, and some of it has been revised several times.

This guidance is not specifically directed at people with mental disorders, but is of importance to them both because of the risk that people with conditions such as dementia or learning disability may experience discrimination in access to healthcare, and because some decisions may be made when people without a prior disability are too ill to make a competent treatment decision.

On 3rd April, two significant and linked documents were issued: Covid-19 Guidance: Clinical Advice 56 and COVID-19 Guidance: Ethical Advice and Support Framework. 57 These were particularly concerned with the risk that the need for healthcare resource may exceed what was required, and that ‘changes to healthcare delivery and scope may be necessary’, presumably meaning that there may need to be a more restrictive prioritisation of access to critical care and particular treatments such as ventilators (although the Clinical Advice also suggested 58 that further guidance would be issued in the event that an ‘extreme surge’ was experienced, where capacity within the system was exhausted).

The ‘Key Recommendations’ of the Clinical Advice included that:

a) Anticipatory care planning conversations should take place with those who are at higher risk from COVID-19
b) Speciality teams should be encouraged to discuss treatment escalation and limitation plans (TELPS) with patients and/or their families at the earliest opportunity
c) The ethical advice and support framework should be considered together with the most current national decision-making and escalation guidance when making complex decisions.

The Ethical Advice and Support Framework referred to the Clinical Advice, which it asserted was ‘both clinically sound and on firm moral ground’. 59 However, for ‘a small number of complex situations in which additional ethical advice and support may be useful’, it called for each Health Board in Scotland to establish an ethical advice and support group, and stated that a national ethical advice and support group would be established to offer advice and support to local groups, as well as to consider national ethical issues and to offer advice.

A number of organisations, including the Mental Welfare Commission, the Scottish Human Rights Commission, the Health and Social Care Alliance and the Centre for Mental Health and Capacity Law expressed significant concerns about aspects of the guidance. 60 At the time of submission of this article, no updated guidance has been issued, and no public announcement has been made of the membership or terms of reference of the proposed national ethical advice and support group, although we understand that the Scottish Government has had discussions with the Mental Welfare Commission and Scottish Human Rights Commission regarding this.

4.2. Human rights perspective

From a rights-based perspective, particularly in relation to disabled people, there are a number of observations that can be made.

Firstly, it is striking that human rights are not mentioned at all apart from a single reference to the UK Human Rights Act in the Ethical Advice and Support Framework. Yet, several requirements of ECHR and CRPD are clearly engaged, particularly ECHR Article 2 (right to life), Article 8 (right to private and family life), and the requirement of non-discrimination in access to healthcare. 61 This is in contrast to the broader Covid-19 Framework for decision making 62 which sets out the basis on which lockdown restrictions may be eased and which is at pains to emphasise that ‘we must continue to provide additional support for those who need it and seek to advance equality and protect human rights in everything we do’. 63 This may suggest that in Scotland a human rights discourse has become more embedded in mainstream policy making, 64 but in fact health policy remains more guided by traditional principles of medical ethics.

Also, the legal framework within which decisions must be taken is mentioned only in passing. 65 Arguably, the focus is more on providing reassurance that clinicians will not be in legal jeopardy than giving clear advice about what the law (including ECHR) requires. 66 The authorship of both documents was dominated by medical professionals – the Ethical Advice and Support Framework was written by three doctors and a civil servant, and the Clinical Advice had 15 authors, fourteen of whom are doctors. This clinical perspective is obviously vital but, as we

61 See, for example, Scottish Human Rights Commission Letter to Equalities and Human Rights Committee on COVID-19 Emergency Legislation (28 April 2020). Available at: https://www.scottishhumanrights.com/media/2012/letter-in-response-to-ehr-committee-270420.pdf; The ALLIANCE comments on draft COVID-19 clinical and ethical guidance. Available at https://www.alliance-scotland.org.uk/blog/news/the-alliance-comments-on-draft-covid-19-clinical-and-ethical-guidance/; Centre for Mental Health and Capacity Law (1) Comment on Scottish Government CMO COVID-19 Guidance: Clinical Advice (version 2.3), 3 April 2020.Available at: http://blogs.napier.ac.uk/cmhl-mhts/2020/04/08/comment-on-cmo-covid-19-guidance-clinical-advice-version-23-3rd-april-2020/; and (2) Comment on Scottish Government CMO COVID-19 Guidance: Ethical Advice and Support Framework (version 2.2), 6 April 2020. Available at: http://blogs.napier.ac.uk/cmhl-mhts/2020/04/06/comment-on-scottish-government-cmo-covid-19-guidance-ethical-advice-and-support-framework-version-22/.

62 Articles 3 and 25 CRPD.

63 Scottish Government, Coronavirus (COVID-19): Framework for Decision-Making, 23rd April 2020. Available at: https://www.gov.scot/collections/coronavirus-covid-19-framework-for-decision-making/.

64 Ibid, p8

65 See, for example, Scottish Government, COVID-19 Guidance: Clinical Advice, 3rd April 2020, version 2.3. Available at: https://www.gov.scot/publications/coronavirus-covid-19-clinical-advice/

66 Scottish Government, COVID-19 Guidance: Clinical Advice, 3rd April 2020, version 2.2. Available at: https://www.gov.scot/publications/coronavirus-covid-19-ethical-advice-and-support-framework/

67 Ibid, p5.

68 Ibid, p4.
go on to discuss, the impact of this guidance is likely to fall dis-
proportionately on people with disabilities. It is not clear that any disabled
people or organisations of disabled people were consulted in advance of
the issuing of this guidance. This no doubt reflects the urgency of the
situation, but suggests that more may need to done to meet the require-
ments of the CRPD to ‘take into account the protection and promotion of
the human rights of persons with disabilities in all policies and pro-
grammes’ and to ensure that persons with disabilities can effectively and
fully participate in the conduct of public affairs. The 2016 report of the
Special Rapporteur on the Rights of Persons with Disabilities made clear
that this requires ‘prior consultations and engagement with representative
organisations of persons with disabilities at all stages of public decision-
making, including before the adoption of legislation, policies and pro-
grammes that affect them’. A number of important statements by dis-
abled peoples’ organisations and international human rights bodies are
available now which could inform an updated version of this guidance.

Turning to the substantive content of the guidance, a particular area
of concern is that it does not adequately address the need to avoid
discriminatory denial of access to healthcare. Clinicians acting
without an appreciation of this may make decisions whose ethical
justification, and even legality, may be questionable.

As we set out above, the Clinical Advice encourages anticipatory care
planning but arguably focuses less on the need to maximise respect for
patient autonomy, and more on ensuring that people who are perceived
as less likely to benefit will agree not to be admitted to critical care. It
states, for example (emphasis added):

‘To ensure the optimal use of ICU resources, and that patients are
not subjected to futile interventions of no benefit, a realistic as-
seessment of outcomes for different treatment options must be com-
municated to patients, their families or carers in order to facilitate
shared decision making.’

This section states that patients identified as suitable for critical care
should receive a full assessment if their condition deteriorates, in-
cluding the likelihood of provision leading to survival ‘with an accep-
table quality of life’. The concept of quality of life as a criterion for
access to treatment has been criticised by both disability organisations
and also the UN Secretary- General as subjective and potentially
discriminatory. To avoid this it must, at the very least, be made clear
that such an assessment must be made by the patient or, where they
cannot express a view, on the basis of an assessment of their wishes and
feelings. In this respect it is necessary to be mindful that there was
considerable controversy in England as to the extent to which the
Clinical Frailty Score should be used to determine whether patients
would benefit from critical care. Following an outcry from disability
organisations, NICE guidance in England and Wales was amended to
expressly state that it should not be used in younger people, people with
stable long-term disabilities (for example, cerebral palsy), learning
disabilities or autism.

Unfortunately, the Scottish guidance is less clear on this. It does
state that in the context of hospital admissions that clinicians ‘should
have awareness of the Clinical Frailty Score’s limitations particularly
in young patients and those with long-term conditions or disabilities’.
However, it elsewhere states without qualification that there is ‘good
evidence’ regarding the expected benefit (presumably meaning lack of
benefit) of critical care if the person has a Clinical Frailty Score of 5 or
more. This issue was further addressed in a letter (dated 5 May and
published 18 May) from the Principal Medical Officer of the Scottish
Government to Health Boards which referred to the Clinical Advice,
stating that an updated version would be issued once approved, and
further stating that:

“To provide absolute clarity, a stable long-term physical need,
learning disabilities or autism should never be a reason for issuing or
encouraging the use of a DNACPR order. Social care needs, health
conditions or disabilities that are unrelated to a person’s chance of
benefiting from treatment must not be a part of clinicians’ decision
making regarding accessing treatment.”

While this is welcome, the potentially discriminatory approach of the
original guidance is compounded in the Template Treatment
Escalation and Limitation Plan, which lists a set of factors to consider in
setting the level of escalation, including ‘Is the patient dependent for
ADLS (Activities of Daily Living)?’ and ‘Nursing Home Resident’, with
the clear implication that these factors, whatever their cause, weigh
against access to critical care.

The emphasis on anticipatory care planning as a tool for clinical
prioritisation can also be seen in the Anticipatory Care Planning (ACP)
template. Under the heading of a discussion about ‘how would you like
to be cared for?’ the template states that ‘Specific care options e.g.
ventilation in intensive care may not be available or appropriate. You
may wish to explore comfort options such as symptom control as a
priority’. Of course it is right that patients should be given honest and
clear advice about the limits and potential harms of treatment options,
but a more human rights focused approach to anticipatory care plan-
ning would be to emphasise its value in maximising the autonomy of
the patient (in terms of Article 8 of the ECHR) and as a form of support
for decision making (as encouraged by Article 12 of the CRPD).

Another concern about the templates is the apparent lack of any

(footnote continued)
with_disabilities_final.pdf. See also WHO Disability Considerations during the
COVID-19 outbreak, WHO/2019-
nCoV/Disability/2020.1, 2020, p10. Available at: https://www.who.int/
publications-detail/disability-considerations-during-the-covid-19-outbreak
76 NICE, Critical Frailty Scale, 2009. Available at: https://www.nice.org.uk/
guidance/ng159/resources/critical-frailty-scale-pdf-8712262765
77 NICE, COVID-19 rapid guideline: critical care in adults, NG159, 20th March
2020. Available at: https://www.nice.org.uk/guidance/ng159
78 Clinical Guidance, op cit, para 6.1.
79 Op cit, para 7.2.
80 Principal Medical Officer (Scottish Government) Letter to Health Boards on
the use of the Clinical Frailty Scale, 5 May 2020. Available at: https://www.gov.
scot/publications/coronavirus-covid-19-use-of-clinical-frailty-scale—letter
from-principal-medical-officer/
space to document the reasoning behind decisions. As the Royal College of Physicians and Surgeons have stated:

“To provide accountability across the pandemic, documentation of the decision-making process is very important. As far as possible, conclusions should be in writing, and the reasons for any decision should be clearly set out.”

It is particularly concerning that the ACP template conflates two very different situations – where a ventilator is not appropriate, and where it is not available. Clearly the latter situation is much more problematic legally and ethically and, should it happen at all, would require very careful justification.

It may be that some of these issues will be addressed in future iterations of the guidance, but it should be noted that similar problems have arisen with later guidance on emergency department management of suspected adult patients. This brief document is essentially a flowchart, designed to assist in decisions as to whether to admit or discharge patients following initial intervention, and to ensure they spend as little time as possible in the emergency department. There are essentially three outcomes – to admit to hospital (either ICU or High-dependency unit), to discharge because the person is well enough to go home, or to discharge where the patient has an advanced illness. Other than a footnote referencing other guidance, the only explanation of what might inform a discharge of a patient with an advanced illness is as follows:

For patients with advanced illness (DNACPR at home or NH resident)

- Consider Clinical Frailty Score
- Does patient have an Anticipatory Care Plan and/or are they for end of life care?

Again, this fails to recognise the limitations of the Clinical Frailty Score, and implies that having an anticipatory care plan or being a Nursing Home resident is in itself a reason not to admit someone to hospital. Furthermore, it adds having a DNACPR form (do not attempt cardio-pulmonary resuscitation) as an apparent reason not to admit, despite the fact that such status is specific to a particular intervention, not to all forms of critical care. The way in which people have been encouraged to agree to DNACPR forms has been an issue of wider controversy, with the First Minister feeling it necessary to put on record that no-one should feel pushed into agreeing one.

It should be conceded that more recent guidance issued by the Scottish Government is clearer about the way in which anticipatory care planning should operate – for example the updated guidance for care homes issued on 15 May states:

‘Anticipatory care plans do not assume or limit individual choice or decisions. They allow those who provide care to explore and understand what matters most to individuals.'

However, this guidance is issued to people who are supporting the patient before a crisis arises, not clinicians making urgent and vital treatment choices at a time when the patient may be unable to express a view.

5. Conclusion

In some respects, the emergency legislation and clinical guidance can be compared with the Louisa Jordan (in Scotland) and Nightingale Hospitals (in England) which were set up as a result of the pandemic. They were established at great speed in anticipation of a surge of cases which risked overwhelming the system and, at least to date, have not been used to anything like the anticipated extent. As we move now to a phased reduction of lockdown, it may be tempting not to spend too much time scrutinising largely implemented measures which were understandably introduced in haste. However, there are a number of conclusions we can draw which are worth reflecting on as we move to whatever form of ‘new normal’ awaits us.

One is the need to consider human rights in the context not just of formal legal provisions, but in the way the law is applied day to day. To the extent that there may have been failures to respect the human rights of disabled people during the pandemic, they are more likely to have arisen from individual decisions and local policies concerning resource allocation. To date no-one has been detained under a procedure lacking the existing safeguards of the MHA, nor has there been formal rationing of health care, but people may well have lost access to treatment or support which, even in an emergency, they have a legitimate claim to as part of the human right to health.

It is also striking that relatively little attention appears to have been paid in the development of the legislation and guidance to the requirements of the ECHR and CRPD. However, adherence to these principles must, as we have demonstrated, occur. The Scottish legislation was, as usual, certified as compliant with ECHR, but it is arguable that the requirements of ECHR would, if properly understood, vitiate the effect of the changes to the operation of section 13ZA of the SWSA. Additionally, as we set out above, the clinical and ethical guidance was silent on human rights.

More positively, the Scottish emergency legislation did explicitly state that in exercising functions conferred on them, the Scottish Ministers must have regard to opportunities to advance equality and non-discrimination. However, it may be that the full implications of the CRPD approach to equality and non-discrimination have yet to be fully absorbed by policy makers. This, and the lack of engagement with disabled people’s organisations, is something which we believe should be addressed in future legal and policy responses to Covid-19. This would demonstrate a commitment to the requirements of the CRPD to take into account the protection of people with disabilities in all policies and programmes, to consult with people with disabilities, and to promote the training of professionals and staff in the rights recognised in the Convention.

81 Royal College of Physicians, Ethical guidance published for frontline staff dealing with pandemic, 31st March 2020. Available at: https://www.rcplondon.ac.uk/news/ethical-guidance-published-frontline-staff-dealing-pandemic

82 Scottish Government, COVID-19 Clinical Guidance for NHS Scotland: Emergency Department Management of Suspected COVID-19 in Adults 16 April 2020, version 2.0. Available at: https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2020/04/coronavirus-covid-19-clinical-advice/documents/covid-19-clinical-guidance-for-emergency-department-management-of-suspected-adult-patients-16-april-2020/govscot%3Adocument%20Covid-19%20Clinical%20Guidance%20Emergency%20Department%20Management%20of%20Suspected%20Adult%20Patients%2016%20April%202020.pdf

83 The Courier, Coronavirus: Nobody should be pushed into signing ‘do not resuscitate’ forms, says Nicola Sturgeon, 3rd April 2020. Available at: https://www.thecourier.co.uk/fp/news/politics/scottish-politics/1242457/coronavirus-nobody-should-be-pushed-into-signing-do-not-resuscitate-forms-says-nicola-sturgeon/

84 Scottish Government, Coronavirus (COVID-19): clinical and practice guidance for adult care homes, 15th May 2020. Available at: https://www.gov.scot/publications/coronavirus-covid-19-clinical-and-practice-guidance-for-adult-care-homes/

85 Op cit, para 4.3.

86 The increasing controversy over decisions about how people were moved from hospital to care homes is beyond the scope of this article, but may raise similar issues.

87 Section 9 Coronavirus (Scotland) Act 2020.

88 Article 4 (1)(c) and (i) and 4.3 CRPD.
The Scottish Government clearly understood that these changes are highly significant, and it is to their credit that they made clear that the legislative changes would only be introduced if absolutely necessary, and have not in fact done so. The Government also agreed to the establishment of a scrutiny group chaired by the Mental Welfare Commission, with a range of stakeholders, to oversee the operation of emergency powers relating to mental health and incapacity.\textsuperscript{89}

It is also encouraging that the Government has responded to at least some of the criticisms made of their clinical guidance, albeit more slowly than was the case in England and Wales. Moreover, it would, of course, be wrong to be over critical of the Scottish Government’s response at great speed to an unprecedented public health emergency. But a response under stress may demonstrate weaknesses of the current system of legislative and policy development. In normal times, the Scottish Government and Scottish Parliament pride themselves on their participative and inclusive approach to policy development. However, in an emergency, policy gets made by the people ‘in the room’. In this context, the people in the room appear to have been largely health professionals and service providers, not disabled people’s organisations or experts in ethics or human rights.

As we move into the next stage, that is something worth reviewing. In the longer term, it will also be an issue for the review of mental health legislation chaired by John Scott QC to consider, charged as it is with making recommendations that ensure that ‘mental health, incapacity and adult support and protection legislation reflects people’s social, economic and cultural rights including CRPD and ECHR requirements.\textsuperscript{90}

\textsuperscript{89} Mental Welfare Commission for Scotland, Commission Position Statement on Role and Responsibility in relation to coronavirus, 2 April 2020. Available at: https://www.mwcscot.org.uk/news/coronavirus-emergency-legislation-mental-welfare-commission-role

\textsuperscript{90} Scottish Mental Health Law Review website. Available at: https://mentalhealthlawreview.scot/about/