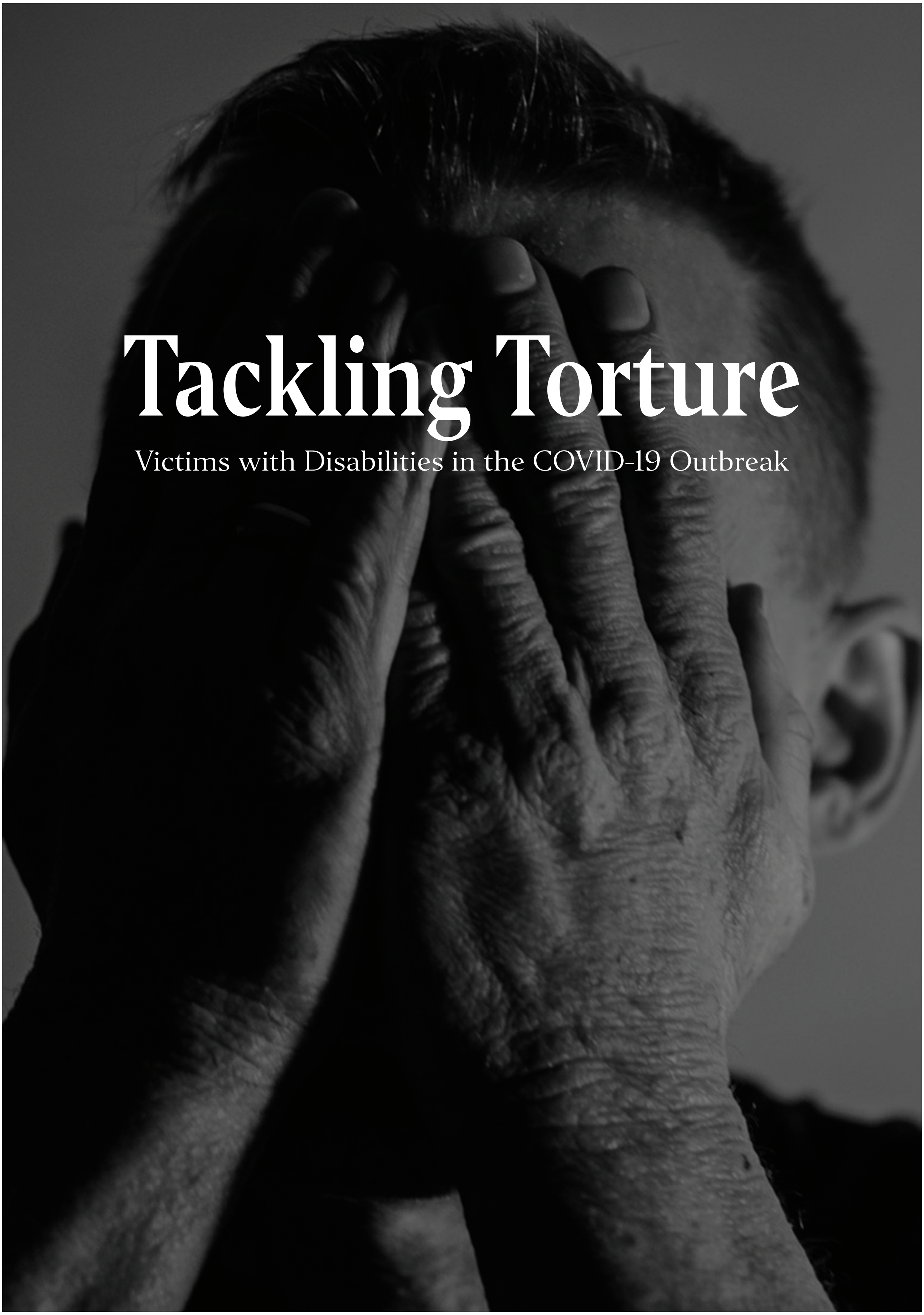

Tackling Torture

Victims with Disabilities in the COVID-19 Outbreak

VALIDITY

This anthology of papers comes out of the Validity Foundation’s 2020 webinar series entitled ’Tackling Torture Against Persons with Disabilities in the Context of the COVID-19 Pandemic’. Recordings of the webinars can be accessed on our website.

**The Validity Foundation –
Mental Disability Advocacy Centre** is an international non-governmental human rights organisation which uses legal strategies to promote, protect and defend the human rights of persons with intellectual disabilities and persons with psychosocial disabilities in Europe and Africa. Validity holds special consultative status with the United Nations’ Economic and Social Council (ECOSOC) and participatory status at the Council of Europe. www.validity.ngo

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Preface

‘Unprecedented’ has become an inadequate and overused description of the dramatic damage that has been wrought during 2020 as the Covid-19 pandemic has raged. The global nature of the catastrophe has affected us all, touching every nation, every community and many of our families. It has also shone a light on how fragile and underprepared our institutions truly were in being able to respond.

During times of crisis, governments are forced to take urgent actions. Yet, few people could have imagined quite how extraordinary some of those measures would be. Few could have predicted how profoundly they would affect our lives. While reports began to surface in late February and early March that the virus had reached Europe, it still seemed incomprehensible that many of our societies would, within weeks, experience dramatic lockdown orders of a form that had never before been considered possible.

Restrictions, quarantine, and physical distancing measures were rapidly introduced in a desperate attempt at halting the progress of a novel and dangerous new disease. Measures that would previously have been regarded as draconian quickly became the norm, with leaders imploring their populaces to restrict their movements and to protect those most vulnerable. Such statements were also backed up with enforcement measures such as curfews, ‘stay at home’ orders and threats of criminal sanction.

Even before the World Health Organization formally declared the pandemic, Validity and our partners began receiving concerning reports that persons with disabilities were being seriously affected. Worryingly, we were hearing that residential institutions were being totally locked down, sometimes with very little notice; a situation that, in some cases, continued for many months. The fear that healthcare systems would become swamped resulted in numerous governments initiating rapidly conceived contingency plans, rationing access to basic and emergency healthcare. Within the first few weeks, we began hearing that persons with disabilities were being turned away from hospitals, ostensibly due to their disability status. The highly communicable nature of the disease meant that many public services were severely restricted or stopped completely, meaning that persons with disabilities no longer received crucial in-home and other community services.

Notwithstanding the enforcement of drastic limits on social contact, Validity also began receiving reports, predictably, that the virus had entered institutions for persons with disabilities in Europe, North America and elsewhere. Mass infections and deaths were an inevitable consequence of keeping people in close quarters. Some countries adopted policies to ‘decongest’ prisons, refugee camps, and even hospitals, yet very few applied this risk reduction strategy in the field of social care. Indeed, to make things worse and as has now become clear, many countries adopted protocols which prevented residents of social care homes from being transferred to hospitals to receive emergency, life-saving treatment after having contracted Covid-19.

These decisions, grounded in faulty presumptions of ‘vulnerability’, have cost countless lives. They have also caused untold levels of pain and suffering, some of which may have been prevented.

From a legal perspective, states have the authority to restrict various liberties and freedoms during periods of emergency. International human rights law recognises this necessity, though not without bounds. Indeed, emergency measures must be carefully calibrated, serve a legitimate purpose, and align with core principles of reasonableness, proportionality, temporal and geographical delimitation. The principle of non-discrimination is one of these, giving rise both to positive and negative obligations on states to prevent harm against specific sub-sections of the population. Even during emergencies, direct or indirect discrimination on the basis of disability is both unethical and unlawful in light of international human rights law.

Denying access to healthcare, reducing or completely halting disability-specific community services, maintaining blanket lockdowns on care homes, and adopting harsh police enforcement tactics have caused serious harm to substantial numbers of persons with disabilities. Keeping people in institutions breaches their rights to independence and community living during normal times. Keeping people in institutions during a pandemic places them at extraordinary levels of danger and has cost countless lives.

Further, it is now clear that persons with disabilities worldwide have, in reality, been disproportionately affected compared with other sections of the population, regardless of the level of development of specific nations. For organisations such as Validity, it came as no surprise to learn of the tragic and disproportionate impact on people with disabilities; more striking, however, is that few states have taken steps to mitigate the harm as weeks turned into months.

As human rights advocates, we are cognisant that some rights must never be restricted. One of these, the prohibition on torture and other forms of ill-treatment, has the status of *jus cogens*. In simple terms, the absolute ban on torture and ill-treatment can never be ignored by states, whether during times of emergency or relative peace. It is also now clearly, from an evidentiary perspective, that restrictions connected to the pandemic have had profound – and disproportionate – effects on persons with disabilities in many countries. Armed with this understanding, it is incumbent on advocates and lawyers to take action where there is evidence that core rights guarantees have been breached, especially where people may have suffered torture and other forms of ill-treatment.

Applying the antitorture framework to the situation of people with disabilities during a pandemic is no simple task. Yet, it is an important one, perhaps most importantly in prompting states to prevent ongoing and future violations from occurring. This is an immensely complex legal undertaking, requiring cumulative assessments of legislation, emergency powers, public health policy and vast quantities of data, while also assessing the levels of harm that have been caused, or that could have been reasonably foreseeable.

This process, which must remain grounded in international human rights law, necessarily gives rise to complicated questions of law, policy and ethics, and indeed the very scope of protection provided under international law.

This anthology cannot answer all of these questions and does not purport to do so. Instead, its single purpose is to promote critical reflection, discussion and debate amongst legal communities and disability rights defenders. Some articles clearly open more questions than they answer, but it is our hope that this collection can stimulate greater levels of action to prevent and redress suffering in the weeks and months to come. It also serves as a launching pad for developing more sustainable, non-discriminatory public policies which protect fundamental human rights, even during periods of crisis.

It is only through adopting a more disability-sensitive approach to disaster planning and recovery plans that we can hope to redress some of the harm that has already been caused.

With our solidarity,

Steven Allen
Co-Executive Director
Validity Foundation – Mental Disability Advocacy Centre

Contributor Biographies

Lisbet Brizuela is Mexican human rights activist with training in special education of children with intellectual disabilities. She is the Director of Disability Rights International's Mexico and Central America regional office based in Mexico City.

Ann Campbell is the Co-Executive Director at Validity. She has three years of experience litigating as a barrister at the Irish Bar and, since then, has worked with several national and international NGOs in Europe, Asia and Africa. Ann brings practical experience and knowledge in the areas of asylum law, women's rights, and LGBTQ rights in addition to her work on disability rights. She has an LLM in International Human Rights Law and over 14 years in national and international law and litigation, litigating at the European Court of Human Rights, the UN Treaty Bodies, the European Committee of Social Rights and, most recently, the European Court of Justice. She is keenly interested in how people's different identities affect their experience of discrimination, and determine the appropriateness of remedies.

Amita Dhanda is Professor of Law at the National Academy of Legal Studies and Research, Hyderabad, for the last 20 years. She also heads the Centre for Disability Studies at the University. An international expert in the field of disability human rights, Dr Dhanda has not just argued for the human rights claims of persons with disabilities but also demonstrated how disability human rights would strengthen the human rights of all. Her book *Legal Order and Mental Disorder* is a pioneering work in the field and her writings on legal capacity of persons with disabilities as well as evolving capacity of the child are widely referred to.

János Fiala-Butora is a Lecturer in International Disability Law at the Centre for Disability Law and Policy, National University of Ireland, Galway, and a human rights attorney with extensive experience representing victims before international human rights bodies. His research focuses on international human rights law, particularly the rights of persons with disabilities and national minorities, international relations, and ethnic conflicts. In the past he served as legal officer of the Mental Disability Advocacy Center (MDAC), Legal Director of the Disability Rights Center (DRC), Executive Director of Minority Rights Group Europe (MRGE), and Executive Director of Validity.

Gábor Gombos is a world-renowned independent disability rights defender. He chaired the European Network of (ex-)Users and Survivors of Psychiatry and co-chaired the World Network of Users and Survivors of Psychiatry. He has been extensively consulted on the rights of persons with disabilities by the United Nations, the World Health Organization and the Council of Europe. Mr Gombos was appointed adjunct professor at NALSAR Law University in Hyderabad, India, in August 2012 and at the NUI Galway, Centre for Disability Law and Policy, in March 2013. Until the end of 2012, Mr Gombos served as a Member of the UN Committee on the Rights of Persons with Disabilities.

David Kabanda is a social rights lawyer with a special interest in social justice in the areas of health, and food systems. He practices this through legal advocacy, training for community empowerment, public interest litigation, research and invoking social equity, fairness and the doctrine of public trust. He studied at Makerere University where he completed a Bachelors of Laws. He did a Post Graduate Bar Course Diploma at the Law Development Centre, Kampala, Uganda, and Masters of Law at Makerere University. He is pursuing his PHD in Law at the University of Western Cape. He has pioneered the justiciability and realisation of social rights in Uganda, East Africa and Africa generally contributing to the growth of jurisprudence in this area. His career is devoted to social inclusion and accountability using human rights-based approaches. He has had tremendous contribution in advocacy and policy development in social rights, working with and helping civil society organisations to appreciate human rights and the use of legal tools for social accountability. He has led constitutional cases and won mental health public interest cases, maternal health rights cases and food rights cases, right to livelihoods, access to medicines, right to a clean and health environment, right to a smoke free environment, access to utilities in hospitals, and access to information to ensure accountability from duty bearers. He is founder and currently the Executive Director of the Center for Food and Adequate Living Rights (CEFROHT).

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Ieva Leimane-Veldmeijere is the Executive Director for ZELDA, an organisation based in Riga, Latvia. The mission of the Resource Centre for People with Mental Disability "Zelda" is to promote de-institutionalisation and development of community based mental health care services for people with mental disabilities through research, monitoring of observance of human rights, legal advocacy and public information and education activities.

Wayne Martin is Professor of Philosophy at the University of Essex, where he is a member of the Essex Human Rights Centre and Director of the Essex Autonomy Project. He also holds an honorary research position with the South London and Maudsley NHS Foundation Trust and is a member of the research team for the Wellcome Trust's Mental Health and Justice project. From 2014-16 he led a team that supported the UK Ministry of Justice in preparation for the review by the United Nations of UK compliance with the United Nations Convention on the Rights of Persons with Disabilities. In 2018 he served on the Equality and Human Rights topic group for the Wessely Review of the Mental Health Act in England and Wales. He holds a BA from Cambridge University and a PhD from UC Berkeley.

Felicia Mburu holds an LLB from Moi University, Kenya and Masters in International Legal Studies specialising in Human Rights Law from American University, Washington College of Law, USA. Felicia is interested in using law to pursue gender justice and the intersection with the rights of persons with disability to legal capacity and to live in the community on an equal basis with others. Felicia currently works with Validity as Africa Litigation Manager.

Bruno Monteiro is the Project Manager for an EU co-funded project entitled Child-Friendly Justice: Developing the concept of social court practices for Validity. Bruno has extensive experience working in the access to justice field as a victim support case-worker, legal researcher and project coordinator in access to justice projects in different NGOs, universities and international governmental organisations. At the United Nations Office on Drugs and Crime and European Union Agency for Fundamental Rights he conducted research and assisted in the management of international projects on crime prevention, juvenile justice, legal aid, victims' and defence rights and algorithmic discrimination. He was also a Coordinator for international research projects where he managed research teams in 28 European countries on topics such as protection of child victims in criminal justice systems.

Thandiwe Mkandawire is a Clinical Social Worker and currently working as the Executive Director for Mental Health Users and Carers Association (MeHUCA), a volunteer-based, patient advocacy organisation for persons with disabilities in Malawi. She is also an Executive Committee member (country representative) for the Global Mental Health Peer Network, (GMHPN) and the Managing Director for Brave Together, a private practice offering psychodynamic therapy and mental health talks to public and private sector organisations.

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Priscila Rodríguez Benavides (LLM) is Associate Director in Disability Rights International's (DRI's) Washington DC office. Prior to this position, she was Director of DRI's Mexico and Central America regional office (2016-2017) and Director of the Women's Rights Initiative for the Americas (2012-2017). She served as a Human Rights Officer and Mental Health Specialist for the United Nations High Commissioner for Human Rights (2017) and as an expert on sexual and reproductive rights and disability for the United Nations Population Fund (2015). She has also been a Faculty Member of the International Disability Law Summer School at the National University of Ireland (2015).

Purwanti Sipora is a woman with a physical disability and uses a wheelchair for mobility. She is the Advocacy and Network Coordinator at the Center for Inclusion and Disability Advocacy Movement (SIGAB). Since 2012, she has handled more than a hundred cases, has assisted people with disabilities in dealing with the law, and has worked a lot with criminal justice professionals in Indonesia. As a DPO in Indonesia, SIGAB has been involved with advocacy that has resulted in the passage of the Government Regulation on Reasonable Accommodation for Persons with Disabilities in the Judicial System in Indonesia. This government regulation is essential in implementing the 2016 Indonesia National Disability Act. SIGAB has been recognised as experts on access to justice for persons with disabilities and provides training to police, legal and paralegal assistants to persons with disabilities in conflict with the law, including gender-based violence cases.

Palik Taslakian is Litigation Manager at Validity Foundation in charge of managing the litigation strategy in a number of European countries. Palik has a Master in comparative criminal law and a Maîtrise in International Law from the University of Paris 1 Pantheon-Sorbonne, focused on international crimes, specifically the crime of genocide. Palik has been working in the humanitarian sector since 2009 and started her journey providing legal support to families of autistic children. She has focused ever since on promoting and defending the rights of vulnerable populations in Europe and the Middle East, working for international human rights organisations and United Nations agencies.

Martin Wathika is a Kenya registered nurse with specialisation in Mental Health/Psychiatric Nursing and Emergency Nursing. He holds a diploma in pharmaceutical technology as well as a certificate in Quality Rights and is an advocate for the rights of persons with mental health conditions. He was involved in the amendment of the Mental Health Bill that is currently being examined by the Kenyan Senate and an implementor of the Kenyan Mental Health Policy. He is currently the Lead Nurse and Project Officer of Kamili Organisation, the only NGO in Kenya delivering community mental health services.

Torture, Disability and COVID-19

Ann Campbell

As the COVID-19 pandemic sweeps the world, it has never been more important to place the prohibition on torture of persons with disabilities front and centre in the fight for human rights. People with disabilities have been hardest hit by the virus, accounting for up to 72% of deaths in some countries.[1] This reality compounds the fact that persons with disabilities have long been subject to some of the most egregious forms of torture and ill-treatment, particularly torture and ill-treatment perpetrated through, and legitimised by, the health and social care systems in developed and developing countries alike. The lives of persons with disabilities, especially those living in institutional settings, must be at the core of our global efforts to combat the virus. And we must take advantage of this moment to eradicate the systematic abuses perpetrated against persons with disabilities.

1. Violations of the Rights of Persons with Disabilities

It is striking that the impacts on persons with disabilities of the pandemic and associated restrictions imposed by governments are so similar in every country. The same issues arise regardless of the level of development of countries or the political system in place. People with disabilities are subject to isolation without access to food in 81 countries, including Belgium, Canada, France, the US, and the UK.[2] Police harassment, torture and murder of persons with disabilities have occurred in the Philippines, Uganda, Nigeria, Russia, Norway and South Africa, and people with disabilities are afraid of leaving their houses because of the police in Italy, the UK, and France.[3] People with disabilities have been left to die of the disease without treatment and are denied access to healthcare for other illnesses.[4] The situation is even worse for those in institutions as governments across the world shut off the limited access they had to the outside world, denying access to the community, visits with family members[5] and, in some cases, preventing physiotherapists and personal assistants from accessing their clients.[6]

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[1] A. Comas-Herrera et al., 'Mortality associated with COVID-19 outbreaks in care homes: early international evidence,', as cited in *United Nations, Policy Brief, A Disability-Inclusive Response to COVID-19* (2020) 5 <https://www.un.org/en/coronavirus/disability-inclusion> accessed 14 December 2020.

[2] Ciara Siobhan Brennan et al., 'Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor' (2020) 31; <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf> accessed 21 December 2020.

[3] Ibid. 33.

[4] 'As if Expendable: The UK Government's Failure to Protect Older People in Care Homes During the COVID-19 Pandemic' (*Amnesty International* 2020) 22

[5] Ciara Siobhan Brennan et al. (n 2) 22 – 27.

[6] See, for example, 'Finland: NGOs seek legal recognition that locking people in institutions is not a lawful response to Covid-19 epidemic' <https://validity.ngo/2020/11/27/finland-ngos-seek-legal-recognition-that-locking-people-in-institutions-is-not-a-lawful-response-to-covid-19-epidemic/> accessed 14 December 2020; and 'Covid-19: Urgent application before French Conseil d'Etat on rights to life and freedom of persons with disabilities' <https://validity.ngo/2020/04/02/covid-19-urgent-application-before-french-conseil-detat-on-rights-to-life-and-freedom-of-persons-with-disabilities/> accessed 14 December 2020.

People were reported to have been left dead in their beds as the virus ran rampant, they experienced extreme neglect, and independent monitoring ceased in many countries.[7]

The similarities suggest that it is the unvarying exclusion, segregation and marginalisation of people with disabilities around the world that has been a determining factor in exacerbating the impact on this group of people. The stereotypes and prejudice that underpin the treatment of persons with disabilities in our societies have played a fatal role in the collective and individual failures of all governments to protect their rights during this crisis.

The role of institutionalisation cannot be underestimated insofar as it is responsible for the lion's share of deaths from COVID-19 in many countries. Government measures in every country have focused on reducing physical contacts between people: maintaining a safe physical distance, banning large and small gatherings, encouraging remote working so as to empty offices, discouraging physical touch, and closing or restricting access to confined spaces such as cinemas, theatres, schools, airplanes and restaurants. By their very nature, institutions render these measures impossible. Institutions foster dependence, including on physical contacts and supports, and operate on the basis of shared space, shared facilities, shared staff, enclosed spaces and group activities.

Institutions comprise those living arrangements described in detail by the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) in its General Comment No. 5 on independent living.[8] The CRPD Committee highlights that institutionalisation deprives people of personal choice and autonomy as a result of the imposition of a certain living arrangement. Some of the characteristics of institutional living described by the CRPD Committee are obligatory sharing of assistants with others, limited or no influence over whom one has to accept assistance from, lack of choice over whom to live with, identical activities in the same place for a group of persons under a certain authority, and usually a disproportion in the number of persons with disabilities living in the same environment.[9] All of these characteristics also increase risk of contracting COVID-19.

Importantly, the CRPD Committee emphasises that an institution is not defined by size: "Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization."[10] As such, 'institutions' include retirement homes for older persons with disabilities, residential schools for children with disabilities, social care institutions, small group homes and other places where persons with disabilities are detained against their will. The global disability rights community has taken up this call

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[7] Ciara Siobhan Brennan et al. (n 2) 22 – 27.

[8] CRPD Committee, *General Comment No. 5 on living independently and being included in the community* (2017).

[9] ibid. para. 16(c).

[10] ibid.

for an end to both large and small institutions, especially for children with disabilities, explicitly condemning the placement of children with disabilities in small group homes as a denial of their right to family life.[11]

In this context, one of the strongest global calls arising from the disability-rights community during the pandemic has been the call for emergency deinstitutionalisation. A term hitherto unknown, it has become a rallying cry[12] and spurred concrete commitment at the level of the CRPD Committee which has established a Working Group[13] to develop practical steps and recommendations to states on emptying institutions safely and ensuring necessary supports in the community in the immediate term.

2. Freedom from Torture under the Law

International law on the prohibition of torture is a key normative framework that adds immense value to the analysis of the experiences of persons with disabilities as human rights violations. This is especially so in the context of the pandemic. Following the prohibition of torture in the Universal Declaration on Human Rights in 1948 (Article 5) and the International Covenant on Civil and Political Rights in 1976 (Article 7), the prohibition was elaborated upon in a dedicated UN convention: the Convention against Torture 1987 (CAT) defines torture in Article 1 and prohibits other acts of cruel, inhuman or degrading treatment or punishment that do not amount to torture in Article 16. A 2002 Optional Protocol to the Convention set up the Sub-Committee on the Prevention of Torture (SPT). This is an international, independent expert body tasked with carrying out independent inspections of places where people are deprived of their liberty with a view to strengthening their protection from torture and other cruel, inhuman and degrading treatment or punishment. Crucially, the Optional Protocol also mandates states to establish at the national level one or more visiting bodies for the same purpose, referred to as “national preventive mechanisms” (Article 3). The Optional Protocol has been ratified by 90 states globally.

The UN Convention on the Rights of Persons with Disabilities (CRPD) is the most recent and comprehensive international instrument for the protection of the rights of persons with disabilities currently in force. It explicitly prohibits torture, cruel, inhuman or degrading treatment or punishment in Article 15. The UN Special Rapporteur on disability relies heavily on this Convention in its work. The UN system also includes a Special Rapporteur on torture. This mandate has contributed significantly to the evolving

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[11] See, for example, the joint position statement issued by eleven disability- and child-rights organisations in 2019 <https://validity.ngo/2019/07/09/all-children-have-the-right-to-family-joint-position-statement/> accessed 14 December 2020.

[12] See, for example, ‘Safety through Inclusion: The case for emergency deinstitutionlisation’, webinar, 11 June 2020 <https://www.facebook.com/ENILsecretaria/videos/2690737837697685> accessed 14 December 2020; and Human Rights Watch, ‘Submission to the UN special rapporteur on violence against women, its causes and consequences regarding Covid-19 and the increase of domestic violence against women’ (3 July 2020) <https://www.hrw.org/news/2020/07/03/submission-un-special-rapporteur-violence-against-women-its-causes-and-consequences> accessed 14 December 2020.

[13] United Nations Office of the High Commissioner for Human Rights, ‘Committee on the Rights of Persons with Disabilities closes twenty-third virtual session’ (4 September 2020). <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=26210&LangID=E> accessed 12 December 2020.

understanding of anti-torture law internationally and in relation to persons with disabilities specifically, most significantly in a 2008 report on torture of persons with disabilities,[14] and a 2013 report on torture in health-care settings.[15]

These UN instruments are supplemented by regional standards – notably in Europe, Africa and Latin America – and many domestic legal systems include their own legislation on torture and ill-treatment. Torture is prohibited in Article 5 of the American Convention on Human Rights and, in the Inter-American Convention to Prevent and Punish Torture. Article 5 of the African Charter on Human and Peoples' Rights prohibits "all forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment" and this provision is expanded upon in a series of soft law instruments and jurisprudence, particularly from the African Commission on Human and Peoples' Rights. The only jurisprudence on torture and disability generated by the Commission, however, is the case of *Purohit and Moore v. the Gambia*, a 2003 case concerning detention of persons with disabilities under the national Lunatics Detention Act.[16] The Commission found a violation of Article 5 of the Charter for inhuman and degrading treatment, although not torture.

In 2018, the African Union adopted a Protocol to the Charter on the Rights of Persons with Disabilities in Africa. Article 10 prohibits torture or cruel, inhuman or degrading treatment or punishment, while Article 11 prohibits harmful practices, such as witchcraft, abandonment, concealment, ritual killings or the association of disability with omens. However, the Protocol requires a minimum of 15 states to ratify it before it enters into force. To date, while nine states have signed, none have ratified it. The African Commission has established the Committee for the Prevention of Torture in Africa which works to ensure the prohibition and prevention of torture and other ill-treatment on the continent. The Committee transmits letters of appeal to states where it has identified that Article 5 of the Charter has been violated, and offers its expertise and initiates resolutions before the Commission on torture-related issues.

In the Council of Europe region, the European Convention on Human Rights, 1950 uses slightly different wording in Article 3, prohibiting torture and "inhuman or degrading treatment or punishment" (rather than "cruel, inhuman and degrading treatment or punishment" which is more commonly used elsewhere). The European Court of Human Right (ECtHR) has evolved a detailed and complex set of case law under this provision, including on torture and ill-treatment of persons with disabilities.[17] Similarly to the UN Committee against Torture (CAT Committee) which monitors compliance with CAT, to determine whether the severity of the suffering rises to the level of torture, the ECtHR takes into account both the subjective and objective experience of the victim, and the cumulative impact of multiple acts, as well as the status of the victim as a person with a disability (among other factors). It has

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[14] Manfred Nowak, *Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak,* A/63/175 (28 July 2008).

[15] Juan E. Méndez, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez*, A/HRC/22/53 (1 February 2013).

[16] *Purohit and Moore v. The Gambia*, Communication no. 241/2001.

[17] See, for example, *Bureš v. Czech Republic* App no 37679/08 (ECtHR, 18 October 2012); *Stanev v. Bulgaria* App no 36760/06 (ECtHR, 17 January 2012); *Blokhin v. Russia* App no 47152/06 (ECtHR, 23 March 2016); and *L.R. v. North Macedonia* App no 38067/15 (ECtHR, 23 January 2020).

also, in practice, considered the failure to provide reasonable accommodations[18] required by the individual as a relevant factor in finding a violation of Article 3 of the Convention – although it does not tend to frame the arguments using CRPD terminology.[19] The European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1989) established the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT). Its mandate is similar to that of the UN SPT, with competence across all 47 member states of the Council of Europe.

The Charter of Fundamental Rights of the European Union, which is the primary human rights instrument within the European Union (EU) and binds the EU's 27 member states, prohibits torture in Article 4. However, the Court of Justice of the EU deals with torture matters mostly in the context of asylum law and the risk of torture of applicants if refouled to a third country outside the EU. It has not yet addressed torture of persons with disabilities.

When examining the measures taken by states in response to the COVID-19 pandemic and their lawfulness in respect of persons with disabilities, national anti-torture and criminal legislation must be taken into account. The CAT Convention and many of the regional conventions require states to enact domestic legislation explicitly prohibiting torture. The extent to which states have complied with this obligation, together with the more general obligation to domesticate international law standards and implement international conventions, is hugely variable. For example, the Slovak Criminal Code prohibits torture and ill-treatment but falls short of the protection standards in Article 16, CAT insofar as it requires intent not just for a finding of torture, but also for a finding of ill-treatment.[20] Uganda, on the other hand, enacted a comprehensive, stand-alone piece of legislation in 2012 prohibiting all forms of torture and ill-treatment. The Second Schedule to the Act contains an extensive and expansive list of acts that comprise torture under the law, including deprivation of food; electric shocks; being tied; rape and sexual abuse; amputation of parts of the body; confinement in a solitary cell; stripping a victim naked; shaving the head of a victim; and "pharmacological torture" such as the administration of drugs to reduce mental competence. All of these are acts to which persons with disabilities are frequently subjected, particularly in health and social care settings.

However, although the Act defines torture in section 2 using a definition similar to that in Article 1, CAT, it omits to codify discrimination as a prohibited purpose for the commission of acts causing pain or suffering.

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[18] According to the CRPD, reasonable accommodation means "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms" (Article 2). The ECtHR does not have a well constructed concept of "reasonable accommodation" but does refer to "accommodations" in its case law in connection with the CRPD.

[19] See, for example, *Blokhin v. Russia* App no 47152/06 (ECtHR, 23 March 2016) where the Court cited arguments by Validity (formerly Mental Disability Advocacy Centre) concerning reasonable accommodation under the CRPD and went on to find a violation of Article 3 for failure to provide necessary medical treatment. See, similarly, *Z.H. v. Hungary* App no 28973/11 (ECtHR, 8 November 2012) para 29.

[20] Criminal Code, Act No. 300/2005, section 420.

It is important to note that, in addition to the codified laws set out above, the prohibition of torture has attained the status of *jus cogens* under international law. It is a peremptory norm giving rise to an obligation for all states to prevent torture and take action against those who carry it out, whether or not they are a party to one of the treaties mentioned above. Further, the right to freedom from torture is absolute and it cannot be derogated from under any circumstances, including war, or, as pertains to the current anthology, for the protection of public health in a global pandemic.

The heightened public awareness of the issues affecting persons with disabilities due to COVID-19 marks a sharp pinnacle in a growing movement to recognise as torture those forms of violence to which persons with disabilities are subjected. As a legal strategy, recognition of the acts of violence perpetrated against persons with disabilities as torture removes these matters from the realm of ethical debate or medical or psychiatric opinion. Institutionalisation, forced interventions, use of restraints, violations of sexual and reproductive rights such as non-consensual abortions or sterilisation, non-consensual drugging, and violence in health and social care settings become questions of non-derogable law. Further, while the CRPD is equally binding, the anti-torture law provides a complementary, well-established legal framework that can support national and international litigation to prevent and redress these acts. As an advocacy strategy, the term “torture” is an emotive and powerful call to action. It is a strong condemnation that draws significant political ramifications and can be an effective rallying cry to mobilise opposition to practices that are too often ignored or even accepted as inevitable. Moreover, and perhaps most importantly, the application of anti-torture law to the experiences of persons with disabilities gives necessary and legitimate recognition to the severity of the violations and the urgent need to eradicate them.

3. Applying Anti-Torture Law to Obtain Effective Redress

The international torture framework should be applied together with the international framework for redress for victims. Torture has been indicated to be a gross and/or serious violation of human rights law,[21] especially where there is a pattern of torture.[22] As such, framing the violations experienced by persons with disabilities as torture strengthens the application of the redress framework.[23] The redress framework can be used to push the often narrow limits of reparations awarded to victims of other forms of human rights violation by moving beyond compensation orders to consider wider forms of reparation.

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[21] See, for example, Council of Europe, ‘Guidelines on Eradicating Impunity for Serious Human Rights Violations’, H/Inf (2011) 7, Section II(3); and OHCHR, ‘The Corporate Responsibility to Respect Human Rights: An Interpretative Guide’, UN, 2012, HR/PUB/12/02, 6.

[22] It has yet to be tried, but there are both ample grounds and ample evidence to argue that the application of forced interventions in psychiatry amounts to a pattern of torture under Article 15 of the CRPD.

[23] Final Report submitted by Mr. Theo van Boven, Special Rapporteur, ‘Study Concerning the Right to Restitution, Compensation and Rehabilitation for Victims of Gross Violations of Human Rights and Fundamental Freedoms’ E/CN.4/Sub.2/1993/8, 2 July 1993 para. 13. Also, as a gross violation of human rights law, torture calls into application the UN Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law, General Assembly Resolution 60/147 of 16 December 2005.

The right to redress under international law comprises the right to an effective remedy and the right to adequate, effective and *comprehensive* reparation.[24] Reparation is understood as encompassing restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition.[25] Importantly, victims of torture are entitled to reparation regardless of whether any perpetrator is identified, apprehended, prosecuted or convicted.[26] There is therefore *no obligation to complete any criminal process* before a victim of torture receives reparations. The ultimate objective of redress is to restore the victim's dignity.[27] Redress procedures as well as reparation must be tailored to the particular needs of the victim – especially important when considered together with the obligation to ensure reasonable accommodations for persons with disabilities at all times,[28] and the obligation to provide both age-appropriate and procedural accommodations for persons with disabilities to ensure their effective access to justice.[29]

The CAT Committee has made starkly clear that, "the provision of monetary compensation only is inadequate for a state party to comply with its obligations [to ensure redress]."[30] This is even more obvious in the case of victims of torture with disabilities who are so often subjected to substitute decision-making regimes either formally (guardianship regimes) or informally (where, in practice, family members or others exercise legal capacity on their behalf). Denial or restriction of legal capacity through substitute decision-making will almost invariably mean that the person concerned cannot freely dispose of their financial assets, including any compensation that may be awarded to them. It is therefore crucial that, when considering what may be appropriate reparation for torture perpetrated during the pandemic, courts, lawyers and human rights defenders look to remedies that provide the possibility of other forms of reparation, in particular rehabilitation, recognition and guarantees of non-repetition which offer more substantial promise of both individual redress and systemic change.

Guarantees of non-repetition may offer one of the strongest opportunities for torture-related litigation to ensure substantial, lasting change for persons with disabilities who are victims of torture on both the individual and structural levels. CAT requires states to issue "effective, clear instructions to public officials on the provisions of the Convention, especially the absolute prohibition of torture."[31] They must also, reform legislation contributing to or allowing torture and ill-treatment, and provide training to public servants, including medical, psychological and social service personnel. The CAT Committee considers that "guarantees of non-repetition offer important potential for the transformation of social relations that may be the underlying causes of violence".[32]

Many of the acts of torture inflicted on persons with disabilities are not recognised as such and are sought to be justified based on the individual's best interests or, as described by a former UN Special Rapporteur on torture, Manfred Novak in 2008,

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[24] Committee against Torture, *General Comment No. 3: Implementation of article 14 by States parties* (2012) para. 2.
[25] ibid.
[26] ibid. para. 3.
[27] ibid. para. 4.
[28] Article 2, CRPD.
[29] ibid. Article 13.
[30] Committee against Torture (n 24) para. 9.
[31] ibid. para. 18.
[32] ibid.

"masked as 'good intentions' of health professionals."[33] Never has this been more evident to the general public consciousness than in the context of the current pandemic where measures such as lockdown in institutions, withdrawal of essential services in the community, and aggressive enforcement of curfews against persons with disabilities are all explicitly justified by governments on the basis both of the protection of the health of persons with disabilities in their best interests and their supposed "especially vulnerable" status.

Even before the outbreak of COVID-19, persons with disabilities and disability-rights defenders have applied the anti-torture framework to highlight that measures commonly accepted within psychiatry and health care systems generally actually amount to torture under international law. For example, in the above mentioned comprehensive report, the UN Special Rapporteur on torture applied the anti-torture framework to violations such as the use of restraints and seclusion; experimentation without informed consent;[34] interventions directed to correct or alleviate impairments; abortion and sterilisation; electroconvulsive therapy; forced psychiatric interventions including forced outpatient treatment; psychiatric medication without consent or as a form of punishment; involuntary detention in psychiatric institutions; and violence, including rape and sexual violence, in institutions. The CRPD Committee has also made clear that forced treatment by psychiatric and other health and medical professionals is a violation of the right to freedom from torture.[35]

The right to guarantees of non-repetition can be used to frame the obligation to prohibit these acts under Articles 12, 14, 19 or 24, CRPD as, *in addition*, part of states' obligations under the right to redress to explicitly issue instructions identifying them as acts of torture.

Turning to the obligation to ensure rehabilitation: Institutions foster dependence and inevitably lead to the loss of or failure to develop skills for independent living. For persons with disabilities who have been affected by lockdown measures imposed in institutions, rehabilitation includes, but is not limited to "re-integrative and social services; community and family-oriented assistance and services; vocational training; education etc."[36] for "the acquisition of new skills required as a result of the changed circumstances of a victim in the aftermath of torture or ill-treatment. It seeks to enable the maximum possible self-sufficiency and function for the individual concerned, and may involve adjustments to the person's physical and social environment. Rehabilitation for victims should aim to restore, as far as possible, their independence, physical, mental, social and vocational ability; and full inclusion and participation in society."[37] It must be "as full rehabilitation as possible".[38] Where disability support services in the community do not exist or are limited and insufficient, the obligation to provide adequate and effective rehabilitation requires states to establish such services for persons with disabilities who have been subjected to torture, especially torture in institutional settings.

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[33] Manfred Nowak (n 14) para. 49.
[34] Explicitly prohibited in Article 15, CRPD.
[35] CRPD Committee, *General Comment No. 1: Article 12: Equal recognition before the law* (2014) para. 42.
[36] Committee against Torture (n 24) para. 13.
[37] ibid. para. 11.
[38] Article 14, CAT.

This complements exactly the obligation on states under Article 19, CRPD to ensure access to general and disability-specific services to facilitate independent living and inclusion in the community.

Finally, the right to guarantees of non-repetition includes the obligation of states to ensure satisfaction and the right to truth to persons with disabilities who are subjected to torture. An often overlooked element of the right to reparation, even within anti-torture law, this is of crucial importance in achieving the ultimate objective of the right to redress – restoring the dignity of the victim. It requires states to make available remedies such as full and public disclosure of the truth, an official declaration or judicial decision restoring the dignity, the reputation and the rights of the victim, and/or public apologies, including acknowledgement of the facts and acceptance of responsibility.[39] For communities of persons with disabilities that are consistently marginalised, ignored and forgotten, and whose experiences are denied, trivialised and dismissed, this can be one of the most powerful means of redressing the power imbalances, discrimination and stigma that underly and enable torture and ill-treatment.

4. Conclusion

While the COVID-19 pandemic and associated human rights violations have undoubtedly caused immediate, on-going and devastating consequences, fundamentally they have simply worsened existing inequalities and discrimination against persons with disabilities. There are certainly new considerations to take into account in this radically changed world but many of the solutions to prevent loss of life and violations of the rights of persons with disabilities have been identified for a long time and form part of the international legal framework. It is past time that the basic guarantees of the CRPD, designed to ensure that persons with disabilities can exercise all their human rights on a basis of full equality with others, are implemented and respected. Increased respect for Articles 12 on legal capacity, 14 on the right to liberty, and 19 on independent living and inclusion in the community can significantly shift the impacts of this pandemic, reducing its disproportionate effect on persons with disabilities. The international anti-torture legal framework (including Article 15, CRPD) and the international redress framework (including Article 13, CRPD on access to justice) are important elements of the toolkit for the protection of the rights and lives of persons with disabilities. Now is the time for creative and innovative legal strategies to drive forward as a matter of extreme urgency the changes for which persons with disabilities have campaigned since the adoption of the CRPD. It is the role of lawyers to make these legal tools available to disability movements in service of this end.

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[39] Committee against Torture (n 24) para. 16.

Protection during the COVID-19 Pandemic: Addressing Systemic Social and Institutional Police Brutality Against Persons with Disabilities

Melanie Kawano-Chiu, Kassim Lawal, Purwanti Sipora, David Kabanda, Bruno Monteiro

1. Introduction

While the novel coronavirus (COVID-19) made masks a ubiquitous sign of covering one's self as a form of protection from the virus, the global pandemic has simultaneously exposed many gaps in protecting the human rights of persons with disabilities.[1] Hasty COVID-19 emergency shelter at home or lockdown orders that did not account for access to food and medication for persons with disabilities coupled with largely inaccessible public information on COVID-19 safety measures resulted in a dangerous situation. Police, tasked with enforcing lockdowns, encountered persons with disabilities leaving their homes to meet their basic needs. With data from 296 respondents around the world on police encounters during COVID-19 collected through the COVID-19 Disability Rights Monitor (DRM), an alarming trend was revealed: police harassment, torture, and killing of persons with disabilities and their family members as punishment for breaking COVID-19 state of emergency regulations.[2] COVID-19 DRM survey respondents reported being beaten or shot by police when out during a lockdown, police harassment of family members trying to contact their loved ones in institutions, and gender-based police brutality against women who broke the curfew rules to seek food, diapers or medication. For instance, a deaf-blind man, William Oloya, who was out after curfew was shot by Ugandan local defence units.[3] In Serbia, a young man with autism was beaten by police on the evening of a protest. In the most extreme cases, breaking curfew rules resulted in death. An Army veteran, Winston Ragos, with post-traumatic disorder was shot and killed in the Philippines.[4] In Kenya, police forces

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[1] In April 2020, the COVID-19 Disability Rights Monitor (DRM) began rapid independent monitoring of state measures concerning persons with disabilities in the context of the COVID-19 pandemic. The COVID-19 DRM was coordinated by the representatives of seven organisations which advocate for the rights of persons with disabilities worldwide, namely the Validity Foundation, the European Network on Independent Living, Disability Rights International, the Centre for Human Rights at the University of Pretoria, the International Disability Alliance, the International Disability and Development Consortium, and the sister organisations Disability Rights Fund and Disability Rights Advocacy Fund.

[2] For more information see COVID-19 Disability Rights Monitor, 'COVID-19 Disability Rights Monitor calls for an end to police violence and abuse against persons with disabilities and their family members' (*COVID DRM*, 4 August 2020) <https://www.covid-drm.org/en/statements/covid-19-disability-rights-monitor-drm-calls-for-an-end-to-police-violence-and-abuse-against-persons-with-disabilities-and-their-family-members> accessed 14 December 2020.

[3] Brian Oduti. 'People with disabilities left stranded during national lockdown in Uganda' (*Global Voices*, 23 June 2020) <https://www.globalvoices.org/2020/06/23/people-with-disabilities-left-stranded-during-national-lockdown-in-uganda/> accessed 14 December 2020.

[4] Vince Ferreras & Gerg Cahiles, 'Retired soldier shot dead by police at checkpoint in Quezon City' *CNN Philippines* (Mandaluyong City, 22 April 2020) <https://www.cnnphilippines.com/news/2020/4/22/Retired-soldier-shot-dead-by-police-.html> accessed 14 December 2020.

killed a man with a physical disability for not wearing a face mask.[5] A video emerged online of a policeman beating, and eventually killing, a man with disabilities who allegedly broke curfew rules in Mozambique. [6] As a result, persons with disabilities from around the world reported that they are living in fear of the police and said that they are afraid to leave their homes.[7]

Yet for persons with disabilities, police brutality is not confined to emergencies or global crises. Research indicates that anywhere from 25 to 50% of people killed by police in the United States of America alone are persons with disabilities.[8] This excessive use of force, which includes beatings, racial abuse, unlawful killings, torture, or aggression against peaceful protestors, is often the result of police brutality. This unlawful use of force by police can result in people being deprived of their right to life, violates the right to be free from discrimination, the right to liberty and security, and the right to equal protection under the law. Such systematic acts of police brutality against persons with disabilities may amount to acts of torture, as defined in Article 1 of the United Nations Convention against Torture (UN CAT).[9]

Unfortunately, police brutality is more than physical acts of violence; violence against persons with disabilities is the institutionalisation of systemic ableism around the world.[10] Police are trained to determine whether or not a person is a threat based on a rigid set of criteria that may include the ability to provide an immediate calm and clear verbal response, cessation of all movement, and acknowledgement of obeying police commands.[11] A person's menace is based on ableist constructions of a person's

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[5] NTV Kenya, 'Police accused of killing disabled man for not wearing mask' (*Youtube*, 25 June 2020) <https://www.youtube.com/watch?v=B7S6ulkn3KY> accessed 14 December 2020.

[6] Club of Mozambique, 'Young man dies in Beira after being beaten by police' *Club of Mozambique* (Maputo, 22 April 2020) <https://www.clubofmozambique.com/news/young-man-dies-in-beira-after-being-beaten-by-police-in-quelimane-policeman-assaults-disabled-person-shows-video-footage-watch-158344/> accessed 14 December 2020.

[7] See COVID-19 DRM (n 2).

[8] Kelley Bouchard, 'Across nation, unsettling acceptance when mentally ill in crisis are killed' *The Portland Press Herald* (Portland, 9 December 2012) <https://www.pressherald.com/2012/12/09/shoot-across-nation-a-grim-acceptance-when-mentally-ill-shot-down/> accessed 14 December 2020; The Washington Post, '2017 United States National Police Shooting' (*The Washington Post*, 2017) <https://www.washingtonpost.com/graphics/national/police-shootings-2017/> accessed 14 December 2020; Abigail Abrams, 'Black, Disabled and at Risk: The Overlooked Problem of Police Violence against Americans with Disabilities' (*Time Magazine*, 25 June 2020) <https://www.time.com/5857438/police-violence-black-disabled>, accessed 14 December 2020.

[9] Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (adopted 10 December 1984, entered into force 26 June 1987) 1465 UNTS 85.

[10] "Ableism may be defined as a belief system, analogous to racism, sexism or ageism, that sees persons with disabilities as being less worthy of respect and consideration, less able to contribute and participate, or of less inherent value than others. Ableism may be conscious or unconscious, and may be embedded in institutions, systems or the broader culture of a society. It can limit the opportunities of persons with disabilities and reduce their inclusion in the life of their communities". Ontario Human Rights Commission, 'Policy on ableism and discrimination based on disability' (2016) <http://www3.ohrc.on.ca/sites/default/files/Policy%20on%20ableism%20and%20discrimination%20based%20on%20disability_accessible_2016.pdf> accessed 15 December 2020; As Harpur explains ableism can be used to "describe conduct that would amount to disability discrimination". Paul Harpur, 'From disability to ability: changing the phrasing of the debate' (2012) 27(3) Disability & Society 325.

[11] Susan Mizner, 'Police 'Command and Control' Culture Is Often Lethal — Especially for People With Disabilities' (*American Civil Liberties Union*, 10 May 2018) <https://www.aclu.org/blog/criminal-law-reform/reforming-police/police-command-and-control-culture-often-lethal-especially> accessed 14 December 2020.

appearance and their ability to produce, excel, and behave.[12] In addition, structural violence against persons with disabilities through social and physical built barriers exist within many legal systems at the national level.[13] Structural violence in regards to encounters with the police or legal system may include a lack of accessible communication, inaccessible built environments, or outright rejection of reports of gender-based violence against women or girls with disabilities.[14]

This article will outline the opportunities for redress through the UN CAT in section two. Section three will outline efforts being made by organisations of persons with disabilities to address systemic and structural ableism in Indonesia, Nigeria and Uganda. Lastly, recommendations are offered on guarantees of non-repetition.

2. Opportunities for Addressing Systemic and Institutional Police Brutality under UN CAT

Police brutality can manifest in several different ways as forms of police violence.[15] Definitions and understanding of it vary. It can encompass different acts ranging from verbal abuse and coercion to assault and murder.[16] For the purposes of this paper it is sufficient to broadly understand police brutality as "unwarranted or excessive and often illegal use of force against civilians" by police.[17] Specifically when taking the form of excessive use of force, police brutality can qualify as torture under the UN CAT. Indeed, there are reports and cases all over the world where police have been found to be intentionally engaging in acts that cause severe pain or suffering, whether physical or mental on a person while they are on duty that reaches the threshold of torture under UN CAT. To be sure, the Convention does not include "pain or suffering arising only from, inherent in or incidental to lawful sanctions" as torture.[18] But it also establishes that use of force should never be disproportionate and excessive, nor serve a discriminatory purpose.[19] Nor can police justify excessive use of force based on wider-ranging police powers borne of emergency decrees to address COVID-19, since obligations under this Convention cannot be derogated even during emergency.[20] The UN CAT is clear that police brutality, when taking the form of excessive use of force

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[12] Talila Lewis, 'Disability Justice Is an Essential Part of Abolishing Police and Prisons' (*LEVEL*, 6 October 2020) <https://level.medium.com/disability-justice-is-an-essential-part-of-abolishing-police-and-prisons-2b4a019b5730> accessed 14 December 2020.

[13] Kathleen Ho, 'Structural Violence as a Human Rights Violation' (2007) 4 Essex Human Rights Review.

[14] The definition of structural violence used here is based on the conceptualisation of the term by Johan Gultang stating that structural violence is due not to "any person who directly harms another person in the structure. The violence is built into the structure and shows up in unequal power and consequently as unequal life chances." Johan Galtung, 'Violence, Peace, and Peace Research' (1969) 6 Journal of Peace Research 167.

[15] Benedict Emesowum, 'Identifying Cities or Countries at Risk for Police Violence' (2017) 21 Journal of African American Studies 269-270.

[16] ibid.

[17] Leonard Moore, 'Police brutality in the United States' (*Encyclopædia Britannica*, 27 July 2020) <https://www.britannica.com/topic/Police-Brutality-in-the-United-States-2064580> accessed 14 December 2020.

[18] See UN CAT (n 9) art 1.

[19] ibid.

[20] ibid.

and when meeting the foregoing elements, triggers several State obligations, even during emergencies, including the obligations to prevent, address and provide redress to victims.[21]

Advocates and victims of police brutality, including persons with disabilities, can rely upon the UN CAT to seek redress. Indeed, the right to redress under the UN CAT requires enacting legislation and establishing complaints mechanisms, investigation bodies, institutions and independent judicial bodies, capable of determining the right to protection from acts of torture or ill-treatment, and the obligation to provide redress.[22] Moreover, State parties must ensure that such "mechanisms and bodies are effective and accessible to all victims", including persons with disabilities.[23] Redress goes beyond establishing a right to an individual remedy or a narrow understanding of reparation, by providing the framework for victims to seek rehabilitation and compensation.[24] The Committee against Torture explains that a right to redress under the Convention goes as far as setting out a duty upon State parties to guarantee non-repetition of torture, which implies the undertaking of institutional and legislative measures and reform to prevent it and guarantee its non-repetition.

It is this guarantee of non-repetition that provides the opportunity to not only seek redress but also wider reform. As the Committee against Torture notes "guarantees of non-repetition offer an important potential for the transformation of social relations that may be the underlying causes of violence and may include, but are not limited to, amending relevant laws, fighting impunity, and taking effective preventative and deterrent measures."[25] States can be held accountable and compelled to acknowledge "past wrongs" and ensure "they are not repeated on society as a whole".[26] As McGonigle Leyh explains, "measures aimed at guarantees of non-repetition link together multiple areas of reform, including their social elements, in order to redress and prevent structural forms of violence."[27] Advocates and victims of police brutality with disabilities can use this framework to seek broader institutional reform. How this can be achieved is locally and culturally specific. Nonetheless the next section illustrates how institutional reform can be achieved in different contexts to address police brutality and to drive institutions in the direction of structural reform, bearing in mind the needs of persons with disabilities.

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[21] See UN CAT (n 9) art 1, 2 and 14.

[22] UN Committee against Torture, *General comment no. 3 (2012): Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment: implementation of article 14 by States parties* (2012).

[23] ibid.

[24] See UN CAT (n 9) art 4.

[25] See UN Committee against Torture (n 22) para 18.

[26] Brianne McGonigle Leyh, 'A New Frame? Transforming Policing through Guarantees of Non-Repetition' (2020) Policing: A Journal of Policy and Practice, paaa035. 5.

[27] ibid. 5

3. Guarantee of Non-Repetition through Institutional and Procedural Reform

As is often the case, addressing systemic change requires countering stigma and discrimination at three levels: individual, societal/community and structural. At the individual level, United States criminal justice and human rights activists like Marlon Peterson remind us that we all need to do the hard internal work of deconstructing our own racist and prejudiced ideas when addressing systemic change such as criminal justice reform. Additional work needs to be done as well to address the inherent and often invisible ableism that contribute to ongoing human rights violations against persons with disabilities. At the community or social level, in the United States and elsewhere around the world, persons with disabilities are looking towards each other for peer support, so that, for example, a community member is called in a time of crisis – rather than the police.[28]

At the structural level, addressing change and redress for instances of police brutality can be framed through the UN CAT. This mechanism along with existing national level opportunities may be needed as reform can become even more complex when legislation, policies, and guidances profess to protect the human rights of persons with disabilities on paper yet are not followed in reality. If written documents were all that were needed to keep persons with disabilities safe during engagements with security forces, then the many documents on safeguarding the human rights of persons with disabilities would be adequate to protect the right to life for persons with disabilities. Instead, efforts by persons with disabilities and their representative organisations to address structural and physical violence against persons with disabilities are needed. Three instances of such efforts in Nigeria, Indonesia, and Uganda are outlined below.

3.1 Institutional Reform for Redress against Police Brutality in Nigeria

There are a number of mechanisms for redress in Nigeria. In fulfilment of Nigeria's obligations under the UN CAT, the Nigerian Constitution guarantees the right to access to court.[29] The Anti-Torture Act 2017 also prescribes 'appropriate penalties' for offenders, taking into consideration the severity of the offence, and gives victims the right to institute civil action in court against offenders for damages.[30] In the promotion of these rights during COVID-19 restrictions, the police authority issued Operational Guidelines for the Police and other Law Enforcement Agencies in Nigeria to guide the conduct of officers on 'enforcement of the COVID-19 prevention regulations'.[31] Specifically, the Guidelines institutionalise 'monitoring and evaluation mechanisms', which places on the police hierarchy and citizens, especially those with genuine complaints, the responsibilities of monitoring and reporting of non-compliance by police officers with

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[28] In the state of Georgia, Disability Link, 'The Disability Link Peer Support Program' (*Disability Link*) <https://www.disabilitylink.org/peer-support/> accessed 14 December 2020; and Project Let's on college and university campuses around the United States provide peer-led communities of support. Lets, 'Project Let's' (*Lets*) <https://www.projectlets.org/chapters> accessed 14 December 2020.

[29] Nigeria, *The Constitution of the Federal Republic of Nigeria* (1999) Section 45.

[30] Nigeria, *The Anti-Torture Act* (2017) Section 4.

[31] Nigeria Police Force, *Enforcement of COVID-19 Regulation: Operational Guidelines for the Police and other Law Enforcement Agencies in Nigeria* (May 2020) 1.

the Guidelines deployed in their localities.[32] It prescribes varying degrees of sanctions, ranging from reprimand to dismissal from service, including criminal prosecution or civil claims in courts, against errant police officers depending on the severity of the offence.[33]

However, despite the laudable provisions of the various legal instruments outlined above, persons with disabilities, who had to break the COVID-19 curfew to seek food or to provide food to others, were victims of police violence. For example, one of the authors of this article, who is a blind man, was attacked by Nigerian police officers during a COVID-19 lockdown. However, the perpetrators of the attack had not been identified at the time of the publication of this article. This lack of action may partly be due to chronic underfunding of the police to carry out a proper investigation. In this case, the monitoring and evaluation measures that should oversee police conduct were not activated.[34] Were they to have been, the identities of the officers on enforcement duties at that material time and in his locality, including the particulars of the van used, would have been found from available records at the local police station. On a different occasion, the author was able to seek redress against two police officers who beat him because his colleague and guide was able to identify the culprits. The likelihood of obtaining evidence, based on cogent and verifiable facts, would have been slim otherwise. When cases of police brutality were reported, the police did not investigate such allegations, ostensibly hiding under the pretext of not having information to trail and identify the erring officers.

One of the main barriers to redress in Nigeria is a basic lack of accessibility of court buildings for persons with disabilities, whether they are lawyers, litigants or witnesses. In recognition of this fundamental need, the Association of Lawyers with Disabilities in Nigeria (ALDIN), an organisation of persons with disabilities, began an advocacy project to eliminate institutional and social barriers in the sector, focusing on the judiciary and the police, in line with the provisions of the Discrimination Against Persons (Prohibition) Act, 2018.[35] Funded by the Disability Rights Fund, the project allows ALDIN to interact with heads of courts in the capital city of Abuja to sensitise court staff on the specific needs of persons with disabilities and the eradication of physical barriers across the courts. Despite a brief delay in the project due to safety considerations in the midst of COVID-19, ALDIN's advocacy has begun to yield positive results with the provision of ramps in some court buildings within Abuja.

3.2 Procedural Reform through Collaboration Between Persons with Disabilities and Police in Indonesia

Police violence against persons with disabilities in Indonesia typifies structural violence. Sasana Inklusi dan Gerakan Advokasi Difabel (Inclusion and Disability Advocacy Movement Organisation (SIGAB)), an organisation of persons with disabilities in Indonesia has found: 1) rejection of reports of violence against women and girls with disabilities, whether the reports are submitted by persons with disabilities themselves or by their families, because the police find it difficult to prove the testimony of persons with disabilities; 2) discrimination and degradation in examining persons with

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[32] ibid. 7.
[33] ibid. 8.
[34] ibid. 4.
[35] Nigeria, *The Discrimination Against Persons (Prohibition) Act* (2018) Sections 6, 7 and 8.

disabilities as victims of violence when the police ask questions that are gender- or disability-biased - for example, *"Do you like him"* (the perpetrator of violence)? *"Did you feel happy when he fucked you?"*; 3) undue dependence on the victim to provide evidence and witnesses of the reported case; 4) lack of accessibility and reasonable accommodations in many police stations during examinations of survivors or victims of violence that can retraumatise survivors or exacerbate psychological stress; 5) lack of solutions by the police to address discrimination against persons with disabilities in the judicial process that include neither a standard mechanism of protection for persons with disabilities when they are victims of violence nor a standard referral system for case handling and holistic recovery. If left unaddressed, efforts to prevent and fight impunity of police brutality against persons with disabilities are compromised.

Despite this stark picture, there are also promising examples of how reform can be achieved at a structural level, with the cooperation of civil society and participation of persons with disabilities. SIGAB has developed a partnership with police to develop procedural changes that allow for persons with disabilities to access the legal system in Indonesia.[36] This collaboration between SIGAB and legal enforcement institutions has resulted in amendment of internal and national policies. The development of internal policies of the police and courts to handle cases involving persons with disability before the law has been formalised into standard operational procedures such as:

- Assessment of persons with disability to establish a person's disability status, impairment, and communication requirements to establish reasonable accommodations that will be provided.
- Provision of a legal advisor, lawyer or sign language interpreter that allows for effective communication between the court and persons with disabilities.
- Involvement of physicians, psychologists, and/or other necessary experts.

This collaboration has also positively impacted the perspectives of the police and the courts in the following ways:

- Training for police investigators, and judges, concerning persons with disabilities before the law. The training materials included: Human Rights of Persons with Disability grounded in the United Nation Convention on the Rights of Persons with Disabilities (UN CRPD), policy and laws in Indonesia with regard to access to justice for persons with disabilities, on types of disabilities and how to interact with persons with disability, and legal capacity of persons with disabilities.
- Facilitation of discussion forums to talk about problems related to the investigation process involving persons with disabilities in the justice system. These discussion forums involve strategic stakeholders such as disabled person's organisations, police and institutions involved in handling cases of persons with disabilities such as physicians and psychologists, Ministry of Women Empowerment and Child Protection, Witness and Victims Protection Agency, Judicial Committee, paralegal, lawyers and local governments.

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[36] The project, funded in part by the Disability Rights Fund, started several years ago in the Gunungkidul District of Yogyakarta Province, where SIGAB formalised a partnership with the district Police Station of Gunungkidul and the District Court of Wonosari, Gunungkidul, through a memorandum of understanding.

- Development of research and knowledge products concerning disabilities and law. Research and documentation that has taken place: research and publication of a book concerning the status of persons with disabilities in the justice system, research and publication of analysis of court sentencing in cases involving persons with disability, and research concerning legal capacity of persons with disabilities within the context of civil law.

SIGAB Indonesia has also provided programmes of accompaniment[37] to support and provide assistance to people with disabilities throughout criminal proceedings. Data and the experiences of this organisation of persons with disabilities indicate that with the appropriate support and guidance, cases of violence against persons with disability can be processed through the legal system.

Finally, SIGAB provides another promising example that it is possible to create a referral or forum system at the city, district and provincial levels to improve the accessibility of legal systems for persons with disabilities, with their participation. The forum convenes members of the police, prosecutor, court, service providers, legal aid institutions, organisations of persons with disabilities, and local government. The forum has led structural policy reforms, including: paid DNA tests for legal evidence by the state; adoption of Government Regulation Number 39 concerning Reasonable Accommodation for Persons with Disability involved in the Justice Process; and piloting of a project on the provision of accessibility of infrastructure and information for police and courts based on the principle of inclusive justice.

The examples provided above showcase different measures and approaches that can be adopted to achieve structural reform that contributes towards preventing police brutality and addressing systemic and institutional ableist issues. They also demonstrate how the capacity of police and courts can be improved with the inclusion of persons with disabilities. This includes the joint development of internal police and court policies regarding cases that involve persons with disabilities, accompaniment programmes, and the development of standard operational procedures and referral systems for persons with disabilities to access legal support. As a result, police and courts in these districts have increased their capacity to manage cases involving persons with disabilities in an accessible and safe manner. In addition, police officers and judges have become advocates themselves for the inclusion of persons with disabilities at the sub-national and national levels.

3.3 Redress for Persons with Disabilities who are Victims of Police Brutality during the COVID-19 Pandemic in Uganda

During the strict COVID-19 lockdown, persons with disabilities experienced exceptional police brutality in Uganda.[38] This was because of the indiscriminate application of sanctions against perceived violations of COVID-19 regulations.[39] In the enforcement

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[37] In four other districts/cities in Yogyakarta Provinces and other provinces such as Central Java, East Java, South Sulawesi and East Nusa Tenggara. Between 2012 until 2020, SIGAB has accompanied persons with disabilities in 118 cases. Out of 118 these cases, 95% of them were cases of violence in which the victims were women with disabilities, and 75% of these cases were rape cases.

[38] BBC, 'Uganda - where security forces may be more deadly than coronavirus' *BBC News* (London, 23 July 2020) < https://www.bbc.com/news/world-africa-53450850> accessed 14 December 2020.

[39] ibid.

of the country's lockdown, allegations arose that the army, local defence units and police indiscriminately forced themselves into people's homes and beat them up, including persons with disabilities.[40] On 30 April, for example, police tried to stop a person with psychosocial disabilities in the street, but as he continued walking, security officers shot him in the leg. His leg had to be amputated and he now endures the burden of another layer of disability that could have been prevented.[41] Although this happened, there have not been reparations, compensation and redress to persons with disabilities who have suffered torture, inhuman or degrading treatment at the hands of the police during the pandemic.

Uganda domesticated the UN CAT through the Prevention and Prohibition of Torture Act of 2012. Under this law, there can be no derogation from the enjoyment of the right to freedom from torture.[42] Under the same law, where a victim has a disability, this is regarded as an aggravating factor in disposal of cases. The court is empowered under the law in Uganda to, in addition to any other penalty, order reparations, which may include restitution to the victim, his or her family or dependents to the greatest extent possible. The forms of restitution may include the return of any property confiscated; payment for harm or loss suffered; payment for the provision of services and restoration of rights; or reimbursement of expenses incurred as a result of victimisation.

The foregoing sets a clear framework for persons with disability who have been victims of torture or ill-treatment to access redress. However, these mechanisms have not been readily available in practice to persons with disability, even before the pandemic.[43] At the time of writing, there had not yet been investigations into existing COVID-19 related violations by the government. Previous research has shown a lack of protective measures and trust in criminal procedure in Uganda as factors that reduce the willingness of victims of torture to report.[44] There should be an immediate investigation, prosecution, redress and reparation to victims using internationally accepted standards laid out in the Istanbul Protocol and all other human rights law especially the Convention against Torture, Uganda Constitution under articles 20, 24 and 44, and the Prevention and Prohibition of Torture Act of 2012.

For persons with disability to access justice and get redress, the Government must incorporate and respect the involvement of civil society organisations in the response and provde support for persons with disabilities, particularly those with psychosocial disabilities. This is because without a supportive and protective system, torture victims with disabilities cannot meaningfully access redress and reparations and fight against impunity. A human rights-based approach must be at the centre of any pandemic

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[40] Will de Freitas, 'Uganda's army and violence: how COVID-19 is offering hints of change' *The Conversation* (London, 12 May 2020) <https://www.theconversation.com/ugandas-army-and-violence-how-covid-19-is-offering-hints-of-change-138331> accessed 14 December 2020.

[41] Brian Oduti. 'People with disabilities left stranded during national lockdown in Uganda' (*Global Voices,* 23 June 2020) <https://www.globalvoices.org/2020/06/23/people-with-disabilities-left-stranded-during-national-lockdown-in-uganda/> accessed 14 December 2020.

[42] Uganda, *Prevention and Prohibition of Torture Act of 2012*, Section 3.

[43] International Rehabilitation Council for Torture Victims (IRCT), 'Redress and Reparations for Torture Victims, Data in the fight against impunity thematic report 2017' (2017) <https://www.irct.org/assets/uploads/pdf_20170906093943.pdf> accessed 1 December 2020.

[44] ibid. 32.

response and ought to have been in all the measures that were put in place by the Government. Having persons with disabilities at the table of discussion and planning would help in averting discrimination and overreliance on criminal law.

In addition to the foregoing, it is important that States must enforce the UN CAT, and the laws against torture in respective countries must be enforced. There should be adequate compensation, rehabilitative and protection systems and individual police or security personnel should be held accountable. This will scale down the impunity with which police carry out brutality, especially against persons with disabilities.

4. Conclusion

The COVID-19 DRM survey showcased how the pandemic and restrictive measures to address it aggravated old issues with law enforcement authorities all over the world. Police, empowered to enforce lockdown, curfews and other restrictive measures have engaged in excessive use of force and torture, intentionally inflicting severe pain and even death on persons with disabilities.

The UN CAT establishes a right to redress, which sets out State parties' obligation to provide an individual remedy and guarantee non-repetition of police brutality whenever it reaches the threshold of torture. The guarantee of non-repetition enables advocates and victims of torture to demand for wide ranging reform to address and prevent police brutality, even during emergency situations. Reforms can take different forms. For these to be meaningful to victims of torture with disabilities, these measures must be at individual, community and structural levels and need to address the systemic and institutionalised ableism that drives it. At the structural level, this includes investigation of police and other law enforcement agents on enforcement duties who violate the fundamental rights of persons with disabilities. This cannot be overemphasised with a view to holding them accountable and in order to combat impunity.[45] This is only achievable by activating various institutional mechanisms designed to ensure strict compliance with the rules of engagement, such as those set out in the Police Operational Guidelines in Nigeria.

Similarly, we need to ensure accessible rehabilitation and victim protection and support services, designed and planned in consultation with persons with disabilities to allow victims to feel properly supported to report cases of police brutality. Without this, it reduces the likelihood that victims will report acts of brutality, as has been described in Uganda. In addition, the police must be sensitive to the vulnerabilities of persons with disabilities, and trained on disability-sensitive approaches during emergencies and situations of risks.[46] Measures and reforms proposed in Indonesia, which provide support, referral measures and accompaniment programmes to victims with disabilities show how civil society, persons with disabilities and police can work together to improve access and prevent impunity.

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[45] Ciara Siobhan Brennan et al., 'Disability rights during the pandemic A global report on findings of the COVID-19 Disability Rights Monitor' (2020) 32 <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf> accessed 14 December 2020.

[46] ibid.

To conclude, advocates and victims of torture can and should leverage the UN CAT's right to redress framework to achieve necessary systemic, social and institutional reforms that are so urgently needed to address police brutality. It will allow them to obtain the redress they need in their particular case. It can also contribute to the necessary changes that target underlying factors including ableism that drive police violence against persons with disabilities. These strategies can help to prevent other persons with disabilities from falling victim to police brutality, even during periods of emergency, such as the COVID-19 pandemic.

Discrimination, Triage and Denial-of-Treatment: Lessons from COVID-19 in the UK*

Wayne Martin

1. Squash the Sombrero

In a recent report by Amnesty International, the son of one care home resident in Cumbria (UK) reported on his father's experience during the COVID-19 pandemic:

> From day one, the care home was categoric it was probably COVID and he would die of it and he would not be taken to hospital. He only had a cough at that stage. He was only 76 and was in great shape physically. He loved to go out and it would not have been a problem for him to go to hospital. The care home called me and said he had symptoms, a bit of a cough and that doctor had assessed him over mobile phone and he would not be taken to hospital. Then I spoke to the GP later that day and said he would not be taken to hospital but would be given morphine if in pain. Later he collapsed on the floor in the bathroom and the care home called the paramedic who established that he had no injury and put him back to bed and told the carers not to call them back for any COVID-related symptoms because they would not return. He died a week later.[1]

Based on this report and others like it, Amnesty concluded that the UK Government violated the human rights of care home residents, including the right to life and the right to the highest attainable standard of health. Amnesty does not use the word 'torture' in their report, but they do conclude that "[t]hese decisions and policies … may have violated their right not to be subjected to inhuman or degrading treatment."[2]

What lessons might be learned from the UK's practice of treatment-denial during the first wave of the coronavirus pandemic? In order to tackle this question, we need to reconstruct the policy environment, and the policy imperatives, that shaped the UK's response. In doing so, we can begin from a now-famous press conference at No 10

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[1] Amnesty International, 'As if Expendable: The UK Government's Failure to Protect Older People in Care Homes During the COVID-19 Pandemic' (*Amnesty International* 2020) 22.

[2] ibid 5-6.

Downing Street on 12 March, 2020. British Prime Minister Boris Johnson there introduced his subsequently much-repeated catch-phrase: *Squash the Sombrero.* The expression referred to a graph that was displayed at the press conference. (See Fig. 1.).

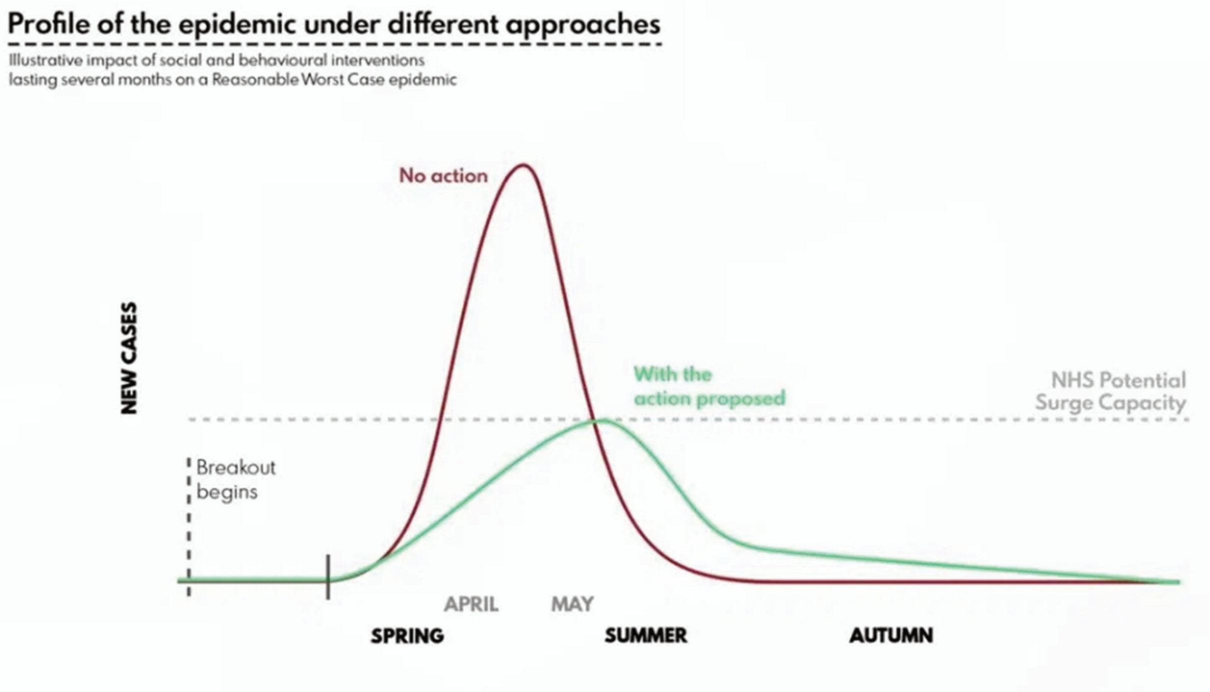

Figure 1: HM Government, 'Profile of the Epidemic under Different Approaches' Press Briefing, 10 Downing St., (12 March 2020).

The graph plotted two curves. The first, labelled "No action" had a shape reminiscent of a traditional Mexican hat. It projected a sharp rise in COVID cases in the UK through the Spring of 2020, followed by a sharp tapering off. The second line, labelled "With the action proposed," showed a slower rise to a lower peak over a longer period. In the Government's graph there was also a third line, labelled "NHS Surge Capacity," representing the maximum number of cases that could be accommodated by the NHS (National Health Service) at any given time.[3] While the first line ("No action") rose far above surge capacity, the second line, in which the sombrero was 'squashed', represented the total number of cases as topping out just within the total capacity that the health system could handle.

Boris Johnson's graph, and its accompanying catchphrase, quickly spread all over the world. It also occasioned controversy. Four days later, the COVID-19 Response Team at University College London (UCL) published its own graph, in a paper signed by 30 co-authors.[4] (See Fig. 2.).

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[3] In the health policy literature, the term 'surge capacity' is defined as "the ability to manage a sudden, unexpected increase in patient volume that would otherwise severely challenge or exceed the present capacity." J Hick and others, 'Health Care Facility and Community Strategies for Patient Care Surge Capacity' (2004) 44.3 Annals of Emergency Medicine 254.

[4] N Ferguson and others, 'Impact of non-pharmaceutical interventions (NPIs) to reduce COVID-19 mortality and healthcare demand' (Imperial College COVID-19 Response Team; 16 March, 2020) <https://doi.org/10.25561/77482> accessed 8 December 2020.

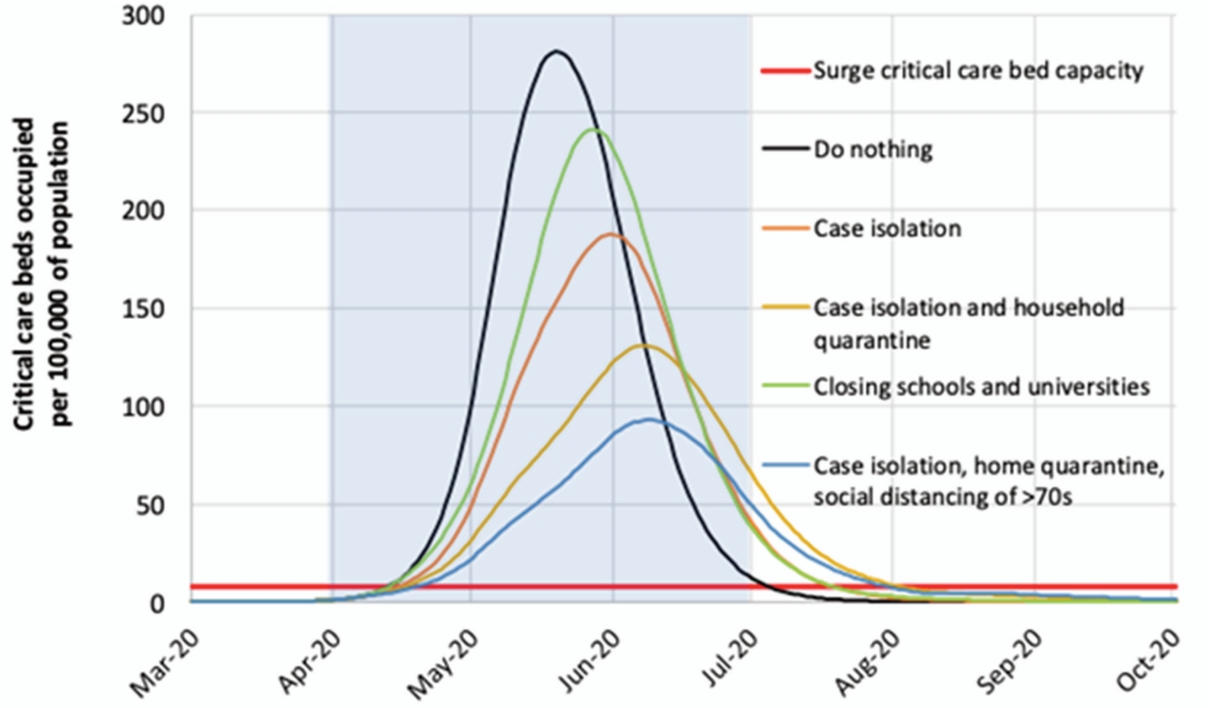

Figure 2: Ferguson et al, 'Impact of non-pharmaceutical interventions (NPIs) to reduce COVID-19 mortality and healthcare demand.' Imperial College COVID-19 Response Team (16 March 2020); <https://doi.org/10.25561/77482> accessed 25 November 2020.

The UCL graph also included an alarming "Sombrero-shaped" curve, together with four further curves with lower peaks, modelling a variety of different policy interventions. Crucially, however, none of the UCL curves managed to stay under the line representing surge critical care bed capacity – a line which hovered disturbingly close to the x-axis. Even the lowest of the UCL curves peaked at nine times NHS critical care capacity. The UCL paper was one of a number of reports that understandably spread alarm among those with responsibility for managing frontline emergency services. It also raised a policy question to which there are no comfortable answers: *How should the health services respond to a situation in which demand for live-saving interventions massively swamps supply?* For the purposes of the present discussion, I refer to such circumstances as *triage situations.*[5]

How can triage situations be managed in a way that is respectful of human rights?[6] One response to this question was offered only a few days later, in a joint statement signed by over 60 officials associated with the UN human rights system. Published by the Office

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[5] My use of this expression is somewhat idiosyncratic, both because there are some forms of triage that do not pertain to life-saving interventions and because (as we shall see) there are some responses to such situations that avoid recourse to triage.

[6] In tackling this question, I am building upon the initial survey of these issues in S Michalowski and others, 'Triage in the COVID-19 Pandemic: Bioethical and Human Rights Considerations' (University of Essex: Joint Technical Report of the Essex Autonomy Project and the Ethics of Powerlessness Project, 6 April, 2020); <http://doi.org/10.13140/RG.2.2.34046.74567> accessed 8 June 2020. For a discussion of human rights issues raised by the use of age as a triage condition, see: S Michalowski, 'The Use of Age as a Triage Condition' in C Ferstman and A Fagan, (eds.) *Covid-19, Law and Human Rights* (University of Essex: Essex Dialogues), 93–100 <http://repository.essex.ac.uk/id/eprint/28027> accessed 26 September 2020.

of the High Commission for Human Rights, the statement delivered its main message already in its headline: "Everyone has the right to life-saving interventions."[7] The body of the statement went on to elaborate the point as follows:

> Everyone, without exception, has the right to life-saving interventions and this responsibility lies with government. The scarcity of resources... should never be a justification to discriminate against certain groups of patients. Everybody has the right to health.[8]

We shall have occasion to return to this UN statement below. But it is important to appreciate the difficulty that it creates for those on the frontline. Put yourself in the position of a manager of an intensive care unit, or the chair of the ethics committee at the hospital where that unit is located. Your immediate and daunting task is to prepare for a situation where there simply are not enough life-saving interventions to go around. The UN statement reminds you that everyone has a right to life-saving interventions. *No exceptions*. But if anything, this only serves to make your problem worse. If demand swamps supply, then not only will you fail to meet patients' medical needs; in doing so you will be violating the human rights of some patients in order to fulfil the rights of others. So whose rights should you prioritise?

2. The British Triage System

Faced with the tragedy of a triage situation, one overarching principle sounds appealing – perhaps even obvious. *If we cannot save everyone then we should at least save as many lives as possible.* This intuitively attractive idea is the animating principle of what is known in the bioethics literature as *the British triage system* – so-called not because its use is confined to the British but because it was first formulated and operationalised by the British Navy in the 19th century.[9] In its original military setting, the strategy was to withhold critical medical resources both from those with "slight injuries" and from those whose injuries are "likely to prove fatal" in order to channel those resources to those in a third category: those who are "seriously injured." In this context, the seriously injured are understood to be those for whom the intervention is most likely *to make the vital difference* – i.e., the difference between living and dying.[10]

The British triage system provides what I shall refer to as a *meta-schema* for the management of triage situations. That is, it provides an overarching policy framework for the distribution of life-saving medical interventions, but by itself it does not suffice to guide practice. In order to do so, it needs to be *specified and operationalised* for application to the circumstances of the public health emergency at hand. In planning

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[7] United Nations Office of the High Commissioner for Human Rights, "No Exceptions with COVID-19: 'Everyone has the rights to life-saving interventions' – UN Experts Say"; <www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25746> accessed 24 May 2020.

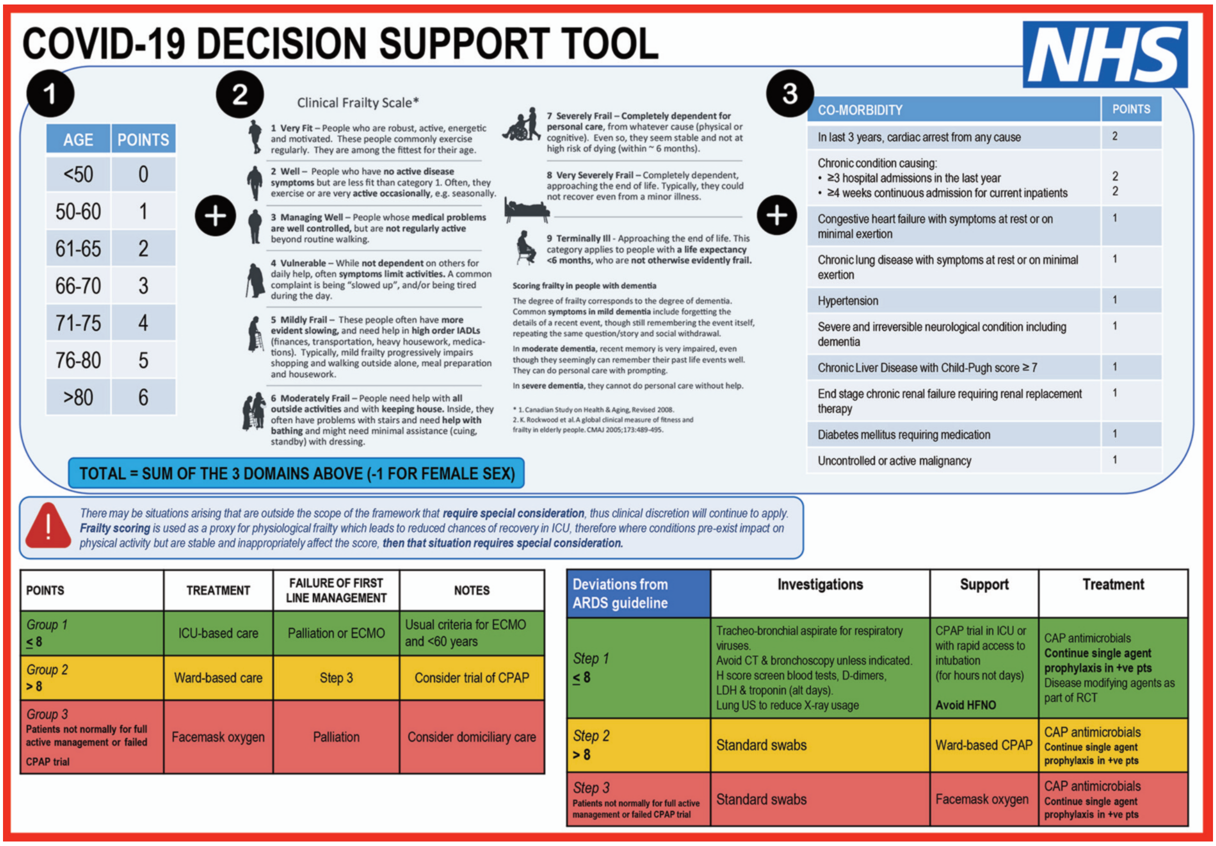
[8] ibid.

[9] On the difference between French and British approaches to triage in the 19th century, see: J Kirby, 'Enhancing Fairness in Pandemic Triage' (2010) 36:12 Journal of Medical Ethics 758; N Okorie, 'Partiality, Impartiality and the Ethics of Triage' (2019) 19 Developing World Bioethics 80.

[10] For the canonical statement of this approach, see J Wilson, *Outlines of Naval Surgery* (McLachlan, Stewart and Co 1846), ch. 3. For a discussion see, J Watt, 'Doctors in the Wars' (1984) 77 Journal of the Royal Society of Medicine 265.

for the anticipated triage situation in the first wave of COVID-19, that meant translating the meta-schema into a concrete plan for prioritising the allocation of intensive care resources (ICU beds, ICU staff, emergency equipment and supplies such as ventilator units and oxygen…) in light of emerging data about which lives were most likely to be saved by deploying them.

In probing the issues raised by the meta-schema, my strategy here will be to consider in detail one controversial specification and operationalisation of it that was developed during the first wave of the pandemic. (See Fig. 3.).



COVID-19 DECISION SUPPORT TOOL

NHS

1

AGE	POINTS
<50	0
50-60	1
61-65	2
66-70	3
71-75	4
76-80	5
>80	6

+

2

Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house.** Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail – Completely dependent for personal care,** from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months,** who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

+

3

CO-MORBIDITY	POINTS
In last 3 years, cardiac arrest from any cause	2
Chronic condition causing: • ≥3 hospital admissions in the last year • ≥4 weeks continuous admission for current inpatients	 2 2
Congestive heart failure with symptoms at rest or on minimal exertion	1
Chronic lung disease with symptoms at rest or on minimal exertion	1
Hypertension	1
Severe and irreversible neurological condition including dementia	1
Chronic Liver Disease with Child-Pugh score ≥ 7	1
End stage chronic renal failure requiring renal replacement therapy	1
Diabetes mellitus requiring medication	1
Uncontrolled or active malignancy	1

TOTAL = SUM OF THE 3 DOMAINS ABOVE (-1 FOR FEMALE SEX)

*There may be situations arising that are outside the scope of the framework that **require special consideration**, thus clinical discretion will continue to apply. **Frailty scoring** is used as a proxy for physiological frailty which leads to reduced chances of recovery in ICU, therefore where conditions pre-exist impact on physical activity but are stable and inappropriately affect the score, **then that situation requires special consideration.***

POINTS	TREATMENT	FAILURE OF FIRST LINE MANAGEMENT	NOTES
Group 1 ≤ 8	ICU-based care	Palliation or ECMO	Usual criteria for ECMO and <60 years
Group 2 > 8	Ward-based care	Step 3	Consider trial of CPAP
Group 3 **Patients not normally for full active management or failed CPAP trial**	Facemask oxygen	Palliation	Consider domiciliary care

Deviations from ARDS guideline	Investigations	Support	Treatment
Step 1 ≤ 8	Tracheo-bronchial aspirate for respiratory viruses. Avoid CT & bronchoscopy unless indicated. H score screen blood tests, D-dimers, LDH & troponin (alt days). Lung US to reduce X-ray usage	CPAP trial in ICU or with rapid access to intubation (for hours not days) **Avoid HFNO**	CAP antimicrobials **Continue single agent prophylaxis in +ve pts** Disease modifying agents as part of RCT
Step 2 > 8	Standard swabs	Ward-based CPAP	CAP antimicrobials **Continue single agent prophylaxis in +ve pts**
Step 3 **Patients not normally for full active management or failed CPAP trial**	Standard swabs	Facemask oxygen	CAP antimicrobials **Continue single agent prophylaxis in +ve pts**

Figure 3: COVID-19 Decision Support Tool; *NHS Dumfries and Galloway Handbook*; <https://www.nhsdghandbook.co.uk/wp-content/uploads/2020/04/COVID-Decision-Support-Tool.pdf> accessed 9 December 2020.

The COVID-19 Decision Support Tool was prominently 'branded' as NHS, and was included in the *Electronic Clinical Handbook* of at least one NHS trust.[11] Nonetheless, its use was never formally authorised or endorsed by the NHS itself; indeed, NHS England ultimately issued a statement distancing itself from the tool.[12] For our purposes here, the

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[11] NHS Dumfries and Galloway Electronic Clinical Handbook <www.nhsdghandbook.co.uk/wp-content/uploads/2020/04/COVID-Decision-Support-Tool.pdf> accessed 9 December 2020.

[12] According to the NHS statement: "The decision-making guidance… derived from work commissioned from an expert group for consideration by Government, which was subsequently stood down on 28/29 March 2020, without DHSC or NHS implementation, after a review of capacity and pandemic trajectory. *It therefore remained in draft and unpublished.*" NHS England, 'NHS and Other Professional Bodies' Response to the Sunday Times' 25 October 2020 <www.england.nhs.uk/2020/10/nhs-and-other-professional-bodies-response-to-sunday-times> accessed 9 December 2020 (emphasis added). The statement quotes the co-chair of one national NHS ethics committee: "We were asked to look at the issue of a Covid-19 triage tool, however, it wasn't needed" (ibid).

Decision Support Tool provides a useful focus for analysis, as it shines a light on some of the finer grain of triage planning and brings some of the key human rights challenges into sharp relief.

The Decision Support Tool operates with a points-based system. Patients with 8 points or fewer are prioritised for ICU admission; those with more than 8 points are directed to care outside an ICU setting, and in the limiting case offered only palliative interventions. Points are allocated in part based on age (with older patients given more points), co-morbidity, gender (women were given a one-point 'discount'), and 'frailty.' The rationale of the tool was to direct ICU treatment towards those who, based on the emerging epidemiological data about mortality rates, were most likely to survive in a COVID ICU setting. Because patients who were older, frailer, ill or male were showing lower survival rates in such settings,[13] the decision tool made it less likely for them to receive ICU treatment.

In considering the inner workings of the Decision Tool, we need to pause over the so-called "Clinical Frailty Index" (or "Rockwood Frailty Scale") that lies at its core. (See Fig. 4.).

Clinical Frailty Scale

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3 Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

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In **severe dementia**, they cannot do personal care without help.

Figure 4: Rockwood Clinical Frailty Scale; NHS Specialised Clinical Frailty Network, "Frailty & COVID-19: Why, What, How, Where & When?"; <https://www.scfn.org.uk/clinical-frailty-scale> accessed 22 November 2020.

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[13] UK Office for National Statistics, 'Deaths Involving COVID-19, England and Wales: Deaths Occurring in March 2020'; <www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingcovid19englandandwales/deathsoccurringinmarch2020> accessed 24 November 2020.

Originally developed by Rockwood and colleagues in the context of a large Canadian study,[14] the Frailty Index in its current form comprises a nine-point scale ranging from 1 ("Very Fit") to 9 ("Terminally Ill"). Each point on the scale is elaborated with a short descriptor combined with a prototypical silhouetted figure. The scale is itself a well-established tool within the NHS, and is endorsed by the NHS Clinical Frailty Network as "a reliable predictor of outcomes in the urgent care context."[15] Its validity has been established on the basis of a number of studies; for example, data from one longitudinal study demonstrated a striking correlation between frailty score and mortality rates over an 800-day period.[16] (See Fig. 5.).

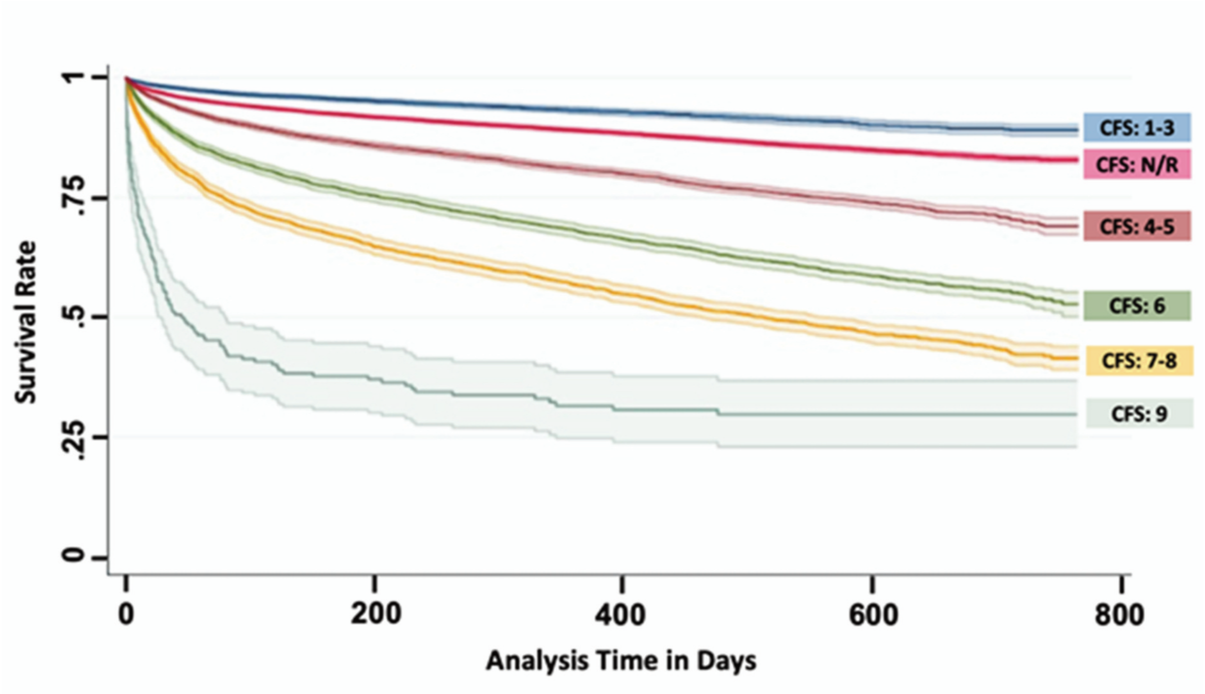

Figure 5: Frailty Scale Scores as Predictor of Mortality Rates; adapted from NHS Specialised Clinical Frailty Network; <https://www.scfn.org.uk/clinical-frailty-scale> accessed 25 November 2020; image credit: Beatrice Carniato.

For our purposes, it is worth taking note of the descriptor associated with the midpoint score on the scale:

> 5. Mildly Frail: These people often have more evident slowing, and need help in high order IADLs [Independent Activities of Daily Life] (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.[17]

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[14] K Rockwood and others, 'A Global Clinical Measure of Fitness and Frailty in Elderly People' (2005) 173:5 Canadian Medial Association Journal 489.

[15] NHS Specialised Clinical Frailty Network, 'Frailty & COVID-19: Why, What, How, Where & When?' <www.scfn.org.uk/clinical-frailty-scale> accessed 22 November 2020.

[16] ibid.

[17] ibid.

Consider how this applies to someone in the position of the care-home resident in Cumbria. As a resident of a care home, it is safe to assume that he requires support in his 'IADLs'. So he would score a minimum of 5 on the frailty scale. His son describes him "in great shape physically," so let's assume he scores zero on co-morbidity. But he is 76-years old, so the Decision Support Tool assigns him another five points for age. That gives him a *minimum of ten points* on the Decision Support Tool, where a score of 8 is the threshold for eligibility for ICU care. And as we know from his son's testimony to Amnesty, he was in fact denied admission to an ICU unit, or even to a hospital ward, and was offered palliative care only (in the form of morphine for pain relief) in the care home setting.

3. Three Levels of Controversy

The COVID-19 Decision Support Tool proved to be intensely controversial;[18] indeed by mid-April NHS England had denounced it. A statement to the press made clear that "[a]ny individual clinician choosing to use this [tool] is doing so against the clear advice of NHS England."[19] So what was the problem with the Support Tool and what lessons can we learn from its failure? For the purposes of our analysis it will be useful to distinguish three distinct levels or categories of concern: (i) concerns about use of the Frailty Index itself; (ii) concerns about the COVID Decision-Tool within which the Frailty Index was embedded; (iii) concerns about the meta-schema that the Decision Tool served to specify and operationalise. I address these three categories of concern in turn.

As already noted, the Rockwood Frailty Scale is a well-validated clinical tool, being validated against other established tools,[20] through inter-rater reliability,[21] and as a statistically reliable predictor of mortality.[22] But as with any tool, it is important to be clear about the differences between the circumstances under which the tool is validated and the circumstances under which it is deployed; in the clinical literature this is the issue known as 'ecological validity.'[23] For example, in one longitudinal study of the tool as a predictor of mortality, assessors were trained in its application; interviews with the patient were supplemented by information gathered from family members or other informants; a final score was assigned only after two separate assessments; and selection criteria excluded both persons under 65 and anyone unable to provide informed consent.[24] Another survival study excluded patients with "cerebral palsy, severe dementia, severe hearing disabilities, or the inability to understand English."[25] This is a far cry from

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[18] See for example: E Harris, Mencap Press Release, 14 April, 2020 <www.mencap.org.uk/press-release/nhs-decision-making-tool-risks-people-learning-disability-being-refused-life-saving> accessed 26 May 2020.

[19] Quoted in 'NHS 'Score' Tool to Decide Who Gets Critical Care' *The Financial Times* (London, 13 April, 2020) <www.ft.com/content/d738b2c6-000a-421b-9dbd-f85e6b333684> accessed 22 May 2020.

[20] Rockwood et al (n 14).

[21] J. Davies and others, 'Inter-Rater Reliability of the Retrospectively Assigned Clinical Frailty Score in a Geriatric Outreach Population' (2018) 21:1 Canadian Geriatrics Journal 1.

[22] NHS Specialised Clinical Frailty Network (n 15).

[23] On the concept of ecological validity, see M. Brewer, 'Research Design and Issues of Validity' in H Reis and C Judd, (eds.) *Handbook of Research Methods in Social and Personality Psychology* (Cambridge University Press, 2nd Edition, 2014) 11.

[24] Rockwood et al (n 14).

[25] J. Lytwyn and others, 'The Impact of Frailty on Functional Survival in Patients 1 Year after Cardiac Surgery' (2017) 154.6 Journal of Thoracic and Cardiovascular Surgery 1990.

the ‘ecological’ circumstances which prevail at the point of hospital admission during a pandemic, where triage decisions must be made quickly; access to family members may be limited; follow-up interviews would come too late to be useful; and the target population includes persons of all ages and (dis)ability, including many who would lack capacity to consent to research participation and/or cannot speak English. In light of these discrepancies, critics expressed doubts about the ecological validity of the frailty index in pandemic conditions.[26] Subsequent research has demonstrated that the Frailty Index is a statistically reliable predictor of mortality in COVID wards,[27] but current guidance nonetheless warns that the instrument is not well-validated for those under 65 and “should not be used in certain groups, including learning disability and cerebral palsy.”[28]

The concerns become more acute when we move to the second level, where we consider the use of the frailty index as one element within the broader COVID-19 Decision Support Tool. As we have seen, the guiding principle of British triage is to direct scarce critical resources to the patients for whom they are most likely to make ‘the vital difference’ – i.e., the difference between living and dying. But does the Decision Support Tool reliably subserve this function? There is indeed considerable evidence that the various *components* of the tool are statistically reliable predictors of mortality among COVID-19 patients: men are indeed less likely than women to survive an ICU COVID-19 ward; older persons are less likely to survive than those who are younger, etc. But we cannot on that basis conclude that the sum of the four constituent scores (age, gender, frailty, co-morbidity) is a statistically reliable predictor of mortality in a COVID ICU ward.

At this second level of controversy we find the ingredients for a legal claim of discrimination. A key underlying problem is that the four variables are not fully independent. People who are older are more likely to have comorbidities; older people with co-morbidities are likely to have higher scores on the clinical frailty scale; and so on. So the underlying risk factors are being doubly or triply counted in the aggregate score. In logical terms there is a risk of the fallacy of composition here: a property of the parts (their being reliable predictors of the ‘vital difference’ in COVID ICU) is assumed to be a property of the whole. In human rights terms, we have the basis for a discrimination complaint. By being denied access to potentially life-saving treatment more frequently than others, members of groups defined by a protected characteristic (age, sex, disability) are treated differently and disadvantageously. Now this in itself is not sufficient to prove discrimination, since differential and disadvantageous treatment can in some instances be justified – provided that it relies on reasonable and objective criteria of differentiation to fulfil a legitimate purpose.[29] In this instance the purpose is clear: saving as many lives as possible. As we shall see presently, even this noble aim

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[26] S Moug and others, ‘Decision-Making in COVID-19 and Frailty’ (2020) 5 Geriatrics 30.

[27] Hewitt and others, ‘The Effect of Frailty on Survival in Patients with COVID-19 (COPE): a Multi-centre, European, Observational Cohort Study’ (2020) 5 Lancet Public Health e444.

[28] A Bloomer, ‘COVID-19: NICE Clarifies Use of Frailty Score in New Rapid Guidance,’ (2020) GM Journal 24 March, 2020 <www.gmjournal.co.uk/covid-19-nice-clarifies-use-of-frailty-score-in-new-rapid-guidance> accessed 26 November 2020.

[29] For this particular formulation of the defence against an allegation of discrimination, see UN Human Rights Committee, *General Comment 18: Non-Discrimination* (1989), para. 13. In UK law, the relevant provision of law refers to a “proportionate means of achieving a legitimate aim.” *Equality Act* (2010), sec. 13(2) and 19(2).

raises some thorny human rights concerns. But the immediate problem at this second level of controversy concerns not the aim but the means of pursuing it. The standing of the COVID-19 Decision Support Tool as a reasonable criterion for differentiation depends on its ecological validity as a predictor of who will (and will not!) benefit from treatment. But the double-counting problem renders this validity doubtful.

The aforementioned problems pale in comparison to the third level of controversy: the meta-schema of the British triage system itself. As we have seen, the ethical intuition underlying the meta-schema seems all but irresistible: in triage conditions, use scarce resources so as to save as many lives as possible. This much might seem obvious. Wouldn't any other use of such resources be a dereliction of duty? If the meta-schema is accepted, then the problems we have canvassed so far are at most flaws of implementation. The Decision Support Tool does not survive scrutiny if it is not properly calibrated to fulfil the imperative of 'British' triage. It therefore seems to fail the 'reasonable means' test. The remedy would be to refine or replace it with a more carefully calibrated tool, supplemented by clinical judgement. Before striking off down that path, however, we need to consider whether that is the right direction-of-travel, when assessed from a human rights point of view.

To see the concern at this third level, we have to come to terms with two simple truths which, taken together, have troubling consequences. The first truth is that the patients who are most likely to survive in a COVID ICU unit are those who had the best pre-morbid health and fitness. The second truth is that various vulnerable populations in our society have, on average, lower health and fitness. The troubling consequence: members of vulnerable populations who are *already* disadvantaged will be *further* disadvantaged by policies which implement the British meta-schema in the context of the pandemic. Alas this 'doubly disadvantaged' group includes both the elderly and persons living with disabilities. These concerns were aptly summed up in a forceful public statement from the CEO of one disability advocacy group:

> [T]his latest Decision Making Tool… presents a double whammy for people with a learning disability, penalising them for needing extra support with everyday activities, as well as for having a neurological condition. Are we reduced to refusing healthy people life-saving treatment because they have a disability? I sincerely hope not.[30]

Despite all these concerns, there is one sense in which the fate of the COVID-19 Decision Support Tool can be viewed as a human rights success story. Frontline practitioners confronted an enormously challenging care-situation which directly threatened the human rights of those affected by it. In response, they designed a principled approach to the problem, and they undertook to be explicit about the basis for the hard choices that were looming. They then shared their tool publicly, facilitating public scrutiny. The critical discussion that ensued in the media and in civil society was informed by human rights standards, particularly with regard to discrimination, and exposed serious human rights concerns. But as the flaws became apparent, the relevant public body quickly and explicitly distanced itself from the tool and made clear that its use was not authorised

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[30] E Harris (n 18).

in the service. All this can be seen as an example of the human rights framework influencing policy and practice in real time, without reliance on the cumbersome mechanisms of judicial review.

4. Alternatives to the Meta-Schema

The failure of the COVID-19 Decision Support Tool seems to leave us back with our original problem. How *should* the health services respond to a situation in which demand for live-saving interventions massively swamps supply? And more specifically: how should policy be designed so as to ensure respect for human rights in such situations? In returning to these questions in light of what we have learned, it will be worth recalling the UN joint statement that we considered at the outset. As we have seen, the'No Exceptions' headline from that statement proved to be ill-suited as a guide to policy formation in a triage situation. But recall how that headline message was elaborated in the body of that statement: "The scarcity of resources… should never be a justification *to discriminate* against certain groups of patients."[31] This elaboration gives a more definite shape to the challenge. Once demand swamps supply, the imperative can no longer intelligibly be to ensure that no one is denied access to live-saving interventions. But we can seek to *avoid discrimination* in making the hard decisions that ensue.

As we have seen, however, avoiding discrimination in triage is by no means straightforward. I have already summarised the case for concluding that the COVID-19 Decision Support Tool is itself discriminatory. The meta-schema of British triage may or may not itself be discriminatory, but its differential impact on already disadvantaged groups raises concerns that are sufficiently serious from a non-discrimination point of view that alternatives must be considered.[32] By way of conclusion I survey four alternatives to the meta-schema. It is not my purpose here to advocate for any one of these alternatives, but it will be worthwhile identifying some of their respective attractions and problems before offering a few final observations.

4.1 Alternative 1: First-Come-First-Served

One simple response to a triage situation would be to allocate available resources to those who present first. Defences of this approach can be found, *inter alia*, in debates within the rabbinical tradition over moral dilemmas created by scarcity.[33] In theological terms, this approach avoids putting doctors in a position where they are 'playing God'

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[31] ibid (n 7) (emphasis added).

[32] On most legal approaches to discrimination, a practice does not amount to discrimination if it is in the service of a legitimate aim and uses a reasonable means for pursuing that aim. As we saw above, the COVID-19 Decision Support Tool fails the *reasonable means* test. But a better calibrated implementation of the underlying meta-schema might well pass that test. If so, then use of the meta-schema would not be discriminatory under the usual 'pragmatic definition' of discrimination. For a recent discussion of the pragmatic definition of discrimination and alternates thereto, see S Gurbai, 'Beyond the Pragmatic Definition? The Right to Non-Discrimination of Persons with Disabilities in the Context of Coercive Interventions' (2020) 22 Health and Human Rights (early online) <www.hhrjournal.org/2020/05/beyond-the-pragmatic-definition-the-right-to-nondiscrimination-of-persons-with-disabilities-in-the-context-of-coercive-interventions> accessed 26 November 2020.

[33] For a recent discussion, see: A Solnica, L Barski and A. Jotkowitz, 'Allocation of Scarce Resources during the COVID-19 Pandemic: A Jewish Ethical Perspective' (2020) 46 Journal of Medical Ethics 444.

in deciding who lives and who dies. In secular terms, it has the advantage of concordance with one important understanding of the basic ethos of medicine: *Aid those who stand before me.* This first alternative was recently endorsed by a German district court judge (Judge Nancy Poser, who is herself living with a serious disability) in an interview with a German journalist. "*Aus ihrer Sicht wäre nur ein Prinzip gerecht: Wer zuerst da ist, bekommt auch die Behandlung.*" ["From her point of view, only one principle would be fair: whoever is there first gets the treatment."][34] But does this approach successfully avoid discrimination? It is far from clear that it does. One problem is that some of the same populations who are disadvantaged under the meta-schema of British triage will also be those who have the least ability to present themselves in a timely fashion for ICU admission. If so, then they might once again find themselves lower down in the queue that determines eligibility for treatment – precisely by virtue of their membership of one of the groups protected under anti-discrimination legislation!

4.2 Alternative 2: Lottery/Randomisation

A second alternative would be to resort to randomisation when demand exceeds supply. This approach has some of the same advantages as Alternative 1 insofar as it takes clinicians out of the role of 'playing God.' In theological terms, a lottery 'leaves the matter to God'; in secular terms, it is 'left to chance.' A further advantage of this approach is that it gives expression, in concrete policy terms, to the idea that every life is of equal worth. However it is important to consider how such a policy would play out in practice, and what impact it might have on those who implement it. As a lived reality, a randomisation procedure would produce situations where an ICU team is instructed by some machine-generated ranking to spend time, energy and resources on one patient while leaving others waiting. If those clinicians can see that their efforts are unlikely to help the first patient but might well save the second (or the second and third...), then the costs in moral distress for the clinicians could be significant.[35] Since moral distress is known to be associated with workforce dropout in critical care services,[36] this could in turn have significant knock-on effects for the health service and hence for the general public. It is perhaps significant to note that a Change.org petition advocating for randomisation at the height of the first wave of the pandemic attracted only about 1,000 signatures.[37]

4.3 Alternative 3: Dilution

This third alternative comes closest to capturing 'the official story' of what happened in the UK during the first wave of the COVID-19 pandemic. The strategy, to put the point somewhat paradoxically, is to respond to a triage situation by *avoiding triage*. To understand this approach, we need to return to the two graphs that we considered

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[34] L. Gather, 'Klage gegen Triage: 'Dann werde ich abgehängt,"*Tagesschau* 17 Nov., 2020; <www.tagesschau.de/inland/verfassungsklage-triage-101.html> accessed 25 November 2020.

[35] On the concept of moral distress, see D Batho, *What Is Moral Distress? Experiences and Responses*, (University of Essex: EOP Green Papers, 2018); <https://powerlessness.essex.ac.uk/moral_distress_green_paper> accessed 26 Novembre 2020.

[36] B Whittaker, D Gillum and J Kelly, 'Burnout, Moral Distress and Job Turnover in Critical Care Nurses' (2018) 3.3 International Journal of Studies in Nursing 108.

[37] M Holmes and J Adams, 'Only a Lottery will Avoid Ventilator Rationing by Privilege' <www.change.org/p/jerome-adams-md-only-a-lottery-will-avoid-ventilator-rationing-by-privilege-6fab9b08-1419-4652-85b8-1ebc9e21a004> accessed 24 November 2020.

at the outset. (See Figs. 1 and 2.) Recall that both graphs included a line that represented 'surge capacity.' Recall also that in each of the two graphs, surge capacity was represented as a horizontal line – that is, as a constant over time. But of course *actual capacity* increased dramatically through a variety of mechanisms: redeployment of staff, deferral of non-critical services, the opening of so-called Nightingale Hospitals, and so on. The aim was to ensure that no one was denied treatment. As we have seen from the Amnesty report quoted at the outset, this aim was not achieved for all – self-congratulatory press statements from Boris Johnson notwithstanding.[38] But pursuit of that aim also came at a cost: the quantity of ICU care was massively increased, but the quality was diluted.

This compromise was powerfully captured by one experienced frontline clinician in NHS Wales, speaking at a webinar held at the end of April:

> In the UK we have *not* moved to a position where critical care is resource-limited. So we have *not* moved to a position where we are having to triage patients on the grounds of limitation of the available resource. But we have only been able to do that by what is called 'surge capacity,' so there has been a massive increase in the amount of critical care that we can deliver – up to about four times the usual number of critical care beds. But the only way to do that is to dilute the critical care resource. We are sharing it out over a large number of patients, but with the same number of intensive care nurses. ... The problem with diluting care is that it does come then with risks. We have had to dilute the standards, and when you dilute the standards, the outcomes get worse.[39]

The opening claim from this frontline report will certainly not ring true to those like the family in Cumbria, who experienced all too palpably the restrictions on access to critical care-resources. But the great advantage of this approach, where it succeeds, is that everyone gets some care, even if the quality of that care is diminished. Moreover, such a plan is powerfully expressive of another ideal that is often expressed (if also unsympathetically received[40]), viz., that *we are all in this together*. But we also have to recognise that the strategy has built-in limits. At some point along the trajectory of dilution, critical care becomes ICUNO – *ICU in Name Only*. And of course if a system finds itself at the terrible crossroads where demand swamps *even surge capacity*, then some method of prioritising must be adopted. As a general solution to the problem of human-rights-compliant-triage, dilution cannot stand alone.

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[38] On 30 April, 2020, Boris Johnson gave a press statement in which he reported: "[A]t no stage has our NHS been overwhelmed. No patient went without a ventilator. No patient was deprived of intensive care." <www.conservatives.com/news/prime-minister-tackling-coronavirus> accessed 30 November 2020. We now know that this claim is not true.

[39] Jack Parry Jones, Oral Statement to the National Mental Capacity Forum (28 April 2020); recording available at <https://autonomy.essex.ac.uk/covid-19> accessed 8 December 2020 (Webinar #2; timestamp: 54:50).

[40] A. Orr, 'Letter to the Editor: We are not all in this together when it comes to Coronavirus' *The Independent*, (London, 15 April 2020) <www.independent.co.uk/voices/letters/coronavirus-lockdown-germany-nhs-scotland-a9465991.html> accessed 25 November 2020.

4.4 Alternative 4: And the Last Shall Be First

I conclude this (non-exhaustive) list with an alternative that was suggested by Amita Dhanda at the Validity Webinar where an earlier version of these remarks was presented. Without presuming to speak for Dhanda, or to put words in her mouth, I understood her suggestion to be that priority should be given to those whose antecedent background situation left them most disadvantaged. Early on in the COVID-19 pandemic, it became clear that the burden of the illness was falling most heavily on certain populations who were already in disadvantaged positions in society. As we have seen, the standard approach of 'British' triage exacerbates that problem, insofar as those very same populations tend to have lower pre-morbid health and fitness and hence, under the British meta-schema, are less likely to receive critical care. Dhanda's proposal would respond to this situation by putting those antecedently disadvantaged populations at the front of the queue in triage situations, even if this means leaving some among the already privileged portion of the population to 'fend for themselves.'[41]

5. Five Lessons from the UK

What lessons should we learn from all this? First and foremost, we have to acknowledge the profound difficulty of ensuring respect for human rights in the particularly challenging circumstances created by pandemic triage situations. It is all well and good to insist that "everyone has a right to health," but it is something else entirely to ensure respect for that right when there is not enough supply of critical resource to go around.

Second, it is important to recognise that responses to triage situations have an ethical substructure. In one respect this may of course seem obvious: the decisions and policies we have been considering are literally matters of life and death; what could be more ethically significant than that? But in the task of developing triage responses, this ethical substructure can sometimes slip from view. Triage policy comes to sound like a task of logistics, maximisation and consequentialist calculation: how can we achieve the maximum benefit and the minimum harm with the limited resources available? (I have heard more than one clinician describe triage as 'a math problem.') But triage situations *become calculable* only insofar as we are already operating within a framework that *renders them calculable*. The meta-schema of the British triage system is one such framework. *The last shall be first* is another. The important point is that these meta-schemas themselves carry ethically substantive commitments. They both reflect and articulate ethical *ideals* that are then *real-ised* (literally: *made real*) in concrete policy and practice.[42]

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[41] Dhanda's proposal resonates with one of the historical alternatives to the British approach to triage. One of the earliest systematic approaches to triage was developed by Dominique Jean Larrey, who was the surgeon general in Napoleon's revolutionary army. Larrey, who is often credited as 'the inventor of triage,' was an extraordinary innovator in military medicine, and developed a novel approach to the treatment of battlefield casualties. Larrey's approach reflected some of the ideals of revolutionary France. Priority for aid should be given to those who are "most dangerously wounded, … without regard to rank or distinction." Moreover, medics should assign a *lower* priority to officers, "who generally have the means of transportation" (i.e., horses) and so are left to fend for themselves. DJ Larrey, *Mémoires de chirurgie militaire et Campagnes* (Smith, 1812), 3:4. Translation by R Hall, *Memoirs of Military Surgery, and Campaigns of the French Armies* (J Cushing; 1814), 2:123.

[42] For a recent exercise using deliberative democracy to choose among resource allocation strategies during the pandemic and to identify the values at work therein, see P Carroll, C Juliette and T Cooper, 'Resource Allocation, Age and COVID-19' (*Ipsos MORI,* 2020) <www.kcl.ac.uk/policy-institute/assets/resource-allocation-age-covid.pdf> accessed 26 Nov., 2020.

Thirdly, when engaging with that ethical substructure, we need to be alive to the possibility that seemingly obvious ethical intuitions ("save the most lives possible") may have unforeseen or unintended consequences when used to guide policy in the extreme conditions of pandemic triage. Some of these consequences raise significant human rights concerns.

Fourth: among those human rights concerns, one issue that looms particularly large is discrimination; I have here been particularly concerned with discrimination on the basis of age or disability. The legal and policy issues here are complex, and the solution is far from obvious. But as we have seen, some well-intentioned responses to the triage challenge fall foul of non-discrimination obligations, and the traditional British triage system itself has consequences that are sufficiently troubling that alternatives must be considered.

Finally, one important lesson that we have learned from the British experience is that robust civil society discourse and debate, guided by sensitivity to human rights norms, can be a significant force in refining policy in real time, even under the extraordinary pressures of a global pandemic. That is certainly a welcome finding, as much remains to be done.

Make the Last First: In Triage Policies and to Prevent Denial of Emergency Health Care Services

Amita Dhanda and Gábor Gombos

1. Introduction

The need to devise triage policies arises when the demand outstrips the resources. The current pandemic had country after country especially in the developed world having to face the question of priority. We are particularly referring to the developed world because unlike the developing and underdeveloped world this question arises for them only in emergency situations. Or rather more correctly it cannot be brushed aside in an emergency. It is not like the deprivation of basic services does not occur in the developed world during non-emergency times, however that denial is not described as a deprivation by the system; it is referred to as the failure or inadequacy of the individual or group. Consequently, the system does not need to assume responsibility for those exclusions. The discourse in the poorer countries stresses on the scarcity of resources, and there is an unspoken understanding that some people will be denied. The system acts according to its embedded hierarchies and questions of prioritisation and the ensuing deprivation are not even raised. It is our position that both affluent and poor countries prioritise even in non-emergency times, it is however not talked about. In the rich countries because the numbers are too small to be accorded political notice and in the poor countries, the denial is seen as inevitable hence not subject to debate. This masked reality has been uncovered by the pandemic – the numbers affected are too many, moreover the people affected are no longer the resourceless, voiceless masses. This altered reality has caused all countries to confront their prioritisation schemes. Who goes first? If it is evident that everyone cannot be saved then who should be first provided relief? This article aims to address this question in relation to persons with disabilities. Where are they in the supplies receiving queue and where should they be?

2. How is the Question Answered in Relation to Persons with Disabilities: the Medical Perspective

The medical model on disability draws attention to the individual person's impairment and concentrates on alleviating it.[1] The medical specialisation working with persons with disabilities was described as defectology. This description captures the medical perspective towards disability. Disability according to the medical perspective represents the deficits of the human body and since the impairment causes the disability, alleviation was possible only be fixing the human body.

The use of the DALY (Disability Adjusted Life Years) standard in evaluating the quality of a disabled life is one more exemplification of the prejudicial medical perspective

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[1] Deborah Marks, 'Models of Disability' (1997) 19 Disability and Rehabilitation 85.

towards disability.[2] Presence of disability by these standards necessarily lower the value of life. A disabled life is thus not accorded its own value instead its value is determined in comparison with the non-disabled life. Since the scale has been premised on the lower value of a disabled life, there is an inherent bias against persons with disabilities in the creation of the scale. And measuring the quality of human life by relying upon such scales makes the prejudice against disability an integral component of the medical perspective.

We refer to the medical model because it encapsulates the medical perspective towards people with disability. If disabled people are seen as defectives by medical personnel, a triage policy driven by medical considerations will not include let alone accord priority to persons with disabilities.

When medical experts are in the driving seat in setting priorities in medical emergencies, the distribution of resources will be commensurate with returns. Consequently, patients with higher chances of recovery would be preferred over those who due to pre-morbidities or age are at greater risk of succumbing. Prioritisation accorded on the basis of medical opinion accords to such opinion an infallibility which may or may not be borne out by evidence. However, the chances of persons with disabilities scoring a low rank in the medical priority list are high.

Even where suggestions are made to formulate triage policies to be administered by non-medical Triage Officers, the prejudice subsisting against persons with disabilities cannot be obviated as these non-medical officers have to make their triage decisions relying upon the judgement of the medical team who as already mentioned would be mired in the medical belief that the quality of a disabled life is at all times lesser than that of a non-disabled one.[3]

Since medical expertise is often deferred to in devising health triage policies, it is necessary to refer to the existence of this prejudice. In the presence of this prejudice, the chances of persons with disabilities obtaining a fair deal in triage policies are small.[4] For that to happen the perspective on disability needs to change. Otherwise even if formal inclusion occurs, as can be seen in the incorporation of disability on the grounds that shall not be considered whilst administering triage, real inclusion will escape persons with disabilities.

3. Socio-economic Determinants of Exclusion

If a country does not have a unified health care system, then the people with resources tend to gravitate to private health care, and when the privileged move away from a service the quality of the public service tends to deteriorate. If the service is unified, then

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[2] Sudhir Anand and Kara Hanson, 'Disability-Adjusted Life Years: A Critical Review.' (1997) 16 Journal of health economics; <https://ora.ox.ac.uk/objects/uuid:1abbc131-a471-49e2-a765-9b99f398f1d0> accessed 14 December 2020.

[3] This article acknowledges that group exclusions are problematic and provides a framework for a more equitable distribution: Douglas B White and Bernard Lo, 'A Framework for Rationing Ventilators and Critical Care Beds During the COVID-19 Pandemic' (2020) 323 JAMA 1773.

[4] On the need to question such expertise see: Andrea Lavazza and Mirko Farina, 'The Role of Experts in the Covid-19 Pandemic and the Limits of Their Epistemic Authority in Democracy' (2020) 8 Frontiers in Public Health < https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7372112/> accessed 14 December 2020.

even as the triage policy is not to be guided by socio-economic determinants, these criteria are found to influence selection. Since a disproportionate number of persons with disabilities are found amongst the poorest, these criteria both influence the quality of the service as well as the apportionment of resources.

To illustrate our contention of socio-economic disadvantage we refer to the health system prevailing in India which is a mix of the public and the private. The impact of this hybrid service on the economically vulnerable in the country was explained by T Jacob John as follows:

> If a rural farmer develops pneumonia, the probability of a cause-specific diagnosis is near zero. A rich business person in a city will most likely get a diagnosis, the cost paid out of pocket. If someone brings in a COVID-19 infection and travels to a place distant from a city, a rural farmer getting COVID-19 is not an unrealistic or far-fetched possibility. Most district hospitals, however, do not yet have influenza diagnostic capacity. If the coronavirus infection reaches an unexpected place, a cluster may develop before the diagnosis is established.[5]

There is an inextricable linkage between the post-disaster effect and the pre-disaster socio-cultural scenario of the affected people. Persons with disabilities along with other vulnerable people are among the worst hit.

It is ironic that the originator of triage, Baron Dominique Jean Larrey[6] undertook to offset the privilege of the rich. Now the situation that one is facing that if there are no triage policies then traditional social hierarchies prevail. And if triage policies exist, they do not provide for persons with disabilities either due to medical or socio-economic bias which prevails against persons with disabilities. To these two biases may be added the additional barrier of non-accessibility, right from non-transparent masks to absence of trained personnel to evaluate the survival possibilities and quality of life of persons with disabilities.[7]

4. An Alternative Perspective

The above analysis shows that persons with disabilities are either not taken into account whilst devising triage and emergency medical services or they are nominally added into policies which were not formulated keeping them in view. A formal inclusion which masks real exclusion.

Our learning from the above analysis is that inclusion cannot be obtained from an exclusionary vision. It therefore seems apposite to turn to a vision which sees disability as an integral part of human diversity and hence seeks policies and programmes which are aimed at real inclusion. The UN Convention on the Rights of Persons with Disabilities

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[5] 'How Prepared Is India to Control the COVID-19 Pandemic?' (2015) 55 Economic and Political Weekly 7.

[6] Phil Nestor, 'Baron Dominique Jean Larrey 1766 – 1842' (2013) 1 Australasian Journal of Paramedicine <https://ajp.paramedics.org/index.php/ajp/article/view/196>.

[7] Satendra Singh, 'Disability Ethics in the Coronavirus Crisis' (2020) 9 Journal of Family Medicine and Primary Care 2167.

(CRPD) was adopted with the active participation of persons with disabilities, celebrates the difference of disability and recognises it as an integral part of human diversity. The CRPD sees inherent value in disability and hence that entire Convention is an effort to ensure the real inclusion of persons with disability.

The right to equality and non-discrimination is both a cross-cutting right as also one of the general principles of the Convention. Consequently, this right extends to all the substantive rights guaranteed by the CRPD. The rights to life, emergency care and health are directly implicated in the context of triage and emergency medical services. The right to life asserts the inherent value of a disabled life. An assertion which aims to displace the majoritarian ableist perspective whereby a disabled life is either not worth living or cannot enjoy the same value as a non-disabled life. Resultant upon this, the right points out that in situations of scarcity, the effort to save a disabled life will be at par with a non-disabled one.

This recognition of inherent value could be severely tested in times of crisis, emergencies and disasters and is recognised in Article 11 which yet again provides that persons with disabilities must be treated on an equal basis with others in terms of prevention, rescue and rehabilitation. Reports on the status of persons with disabilities in the current pandemic however show that the right has been more observed in the breach.[8] The exclusion has happened by either lumping persons with disabilities within general policies without making any provision for the specific needs of persons with disabilities for example in failing to make provision for personnel to communicate with persons with sensory disabilities or having doctors who are equipped to treat a person with disability.

When guidelines of safe conduct are formulated such as prohibiting physical contact or wearing of masks or imposition of lockdown the specific needs of persons with disabilities have not even been normatively acknowledged. Such acknowledgement would have recognised the importance of touch for the deaf-blind, the need for transparent masks which keep the lips visible for the hearing impaired and additional barriers to obtaining support that arose with the lockdown.

Despite the inclusion of article 11 in the CRPD and record ratifications of the Convention, reports of neglect and abandonment of persons with disabilities are coming from all over the world. This indifference to the cause of persons with disabilities or rather regression to the pre-CRPD outlook seems to show that the CRPD has provided a mechanism to seek accountability however it has not changed practice. It is our contention that until persons with disabilities are on the strength of the equality argument only added to a common pool, the story of their neglect is not going to change. Until decision-makers have the freedom to choose between persons with disabilities and the rest, the choice will go against persons with disabilities.

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[8] Ciara Siobhan Brennan, 'Disability Rights during the Pandemic: A Global Report on Findings of the COVID-19 Disability Rights Monitor' (*Africa Portal*, 22 October 2020) < https://www.africaportal.org/publications/disability-rights-during-pandemic-global-report-findings-covid-19-disability-rights-monitor/> accessed 14 December 2020.

If we are expressing dissatisfaction with international human rights law, the logical question is then how should the situation be addressed? In making our suggestion we rely upon an argument set up by Tobin Siebers when he was required to consider what should be the criterion for recognising personhood?[9] Siebers rejected the celebrated criterion of reason as in his view this criterion was possessed by the privileged and hence could not protect the disadvantaged from exclusion, either on the ground that they did not possess enough of it or it was not the right kind. He was of the view that the defining criterion should be such that it results in the disadvantaged being centred and the privileged pushed to the margins. To this end Siebers proposes the standard of fragility. This standard he contended would ensure that in any situation of choice and selection, the most disadvantaged cannot be excluded as they epitomise the standard.

It may be recalled that when Barron Larrey proposed triage to rescue the wounded from the battlefield, he did it to reverse the advantage of rank and privilege. Prior to the triage proposed by Larrey it was persons of rank and privilege who were first rescued from the battlefield. The standard that those most in need of care should receive it ensured that social status did not determine access to medical services.

By both altering the direction of the queue and the criterion of selection we believe we are introducing a scheme which ensures that persons with disabilities are not left out. Since the last have to come first any scheme or programme which leaves them out is clearly illegitimate and illegal. The present “best chance to survive standards” can exclude persons by reason of disability and yet pass off the effort as legitimate and legal. Since there is an inbuilt scope for exclusion in the standard, the exclusion can be done without any moral qualms of doing anything wrong. The ‘last goes first standard’ makes the personnel doing triage confront the exclusion. They may still go ahead and leave behind but this round they would have to do in clear knowledge that they were doing something which is impermissible. Since the discomfiture in doing the illegal is real for most good people and even bad people would fear of legal consequences, this standard provides the best chance of inclusion for persons with disabilities.

It could be contended that even if the standard looks attractive from the standpoint of persons with disabilities, it would attract the charge of unreasonableness from the non-disabled. Advocacy pressing for the inclusion of vulnerable persons should not be metamorphosed into only seeking their inclusion and the exclusion of all else. The standard we would submit is not aiming to do so, rather it is seeking for enough tilting of balance that the shadow of vulnerability also falls on the alleged non-vulnerable. Once the shadow falls on them, they also become eligible for inclusion. This entry, however happens by reason of their vulnerability and not some ostensible strength. Incorporation of the non-disabled through this procedure increases the quotient of human solidarity and connectedness. It is in human-interdependence rather than independence lies the salvation of the human species. The celebration of human reason, autonomy and independence has only brought the human species to the door of extinction. The pandemic has brought home our inter-connectedness and we can address it guided by the same values which have brought us here; or propose a change of direction. We opt for change.

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[9] Tobin Siebers, ‘Disability and the Right to Have Rights’ (2007) 27 Disability Studies Quarterly <https://dsq-sds.org/article/view/13> accessed 14 December 2020.

5. Conclusion

The system of triage and emergency medical services have largely been formulated employing utilitarian considerations. Implementation of the standard of the greatest good of the greatest number is necessarily informed by how good is defined. In our exposition, we have pointed to the systemic prejudice subsisting against persons with disabilities causes their exclusion by default. The CRPD with its commitment to having persons with disabilities being treated on a equal basis with others has allowed for an outrage being expressed against the exclusion. The pre-CRPD outlook perceived the exclusion as natural and automatic. The CRPD with its stress on universal access and reasonable accommodation is pressing for the inclusion of persons with disabilities but in a ableist world. A strategy which may work in non-emergency situations but would be insufficient in a state of catastrophe. The criterion in disastrous scenarios like the present pandemic require extreme measures like changing the systemic default. In making the last first we are proposing the boarding sequence followed in aircrafts, where persons with disabilities are allowed to alight first as that ensures they are neither trampled over nor left behind.

Effects of COVID-19 Restrictions on Persons with Mental Disabilities in Kenya

Martin Wathika and Palik Taslakian

1. Introduction

The National Influenza Centre Laboratory at the National Public Health Laboratories of the Ministry of Health confirmed a Coronavirus disease (COVID-19) case in Nairobi on 12th March 2020, the first in Kenya since the beginning of the outbreak in China in December 2019. The case was of a Kenyan citizen who travelled back to Nairobi from the United States of America via London on 5th March 2020. *'We wish to assure all Kenyans that the Government will use all the resources available to fight coronavirus,'* Health Cabinet Secretary Mutahi Kagwe declared.

2. Overview of the Situation of Persons with Disabilities in Kenya

2.1 The Situation During the Pandemic

Immediately after the detection of the first COVID-19 case, the government installed restrictive measures to contain the spread of the virus. The measures imposed on the general population mainly consisted in closing all schools and workplaces but provided for exceptions for persons providing essential services. Domestic and international flights were prohibited, as well as social gatherings. Quarantine for travellers and social distancing were imposed and wearing a mask in public became mandatory. Freedom of movement was restricted in the capital city and its surroundings, and a 7pm to 5am curfew was imposed.

The government focused strictly on the physiological aspect of the pandemic and all efforts, information and restrictions were guided by the ultimate goal of containing and restricting the spread of the virus. Health messages in the media and from authorities emphasised hygiene measures to prevent the transmission and further outbreaks of COVID-19, with little general education on psychosocial disability. The government of Kenya updated Kenyans on the daily situation through a press conference by the Cabinet Secretary for Health. While this initiative satisfied the obligation to provide information to citizens, it did not respond to the anxiety and fear of the unknown.

Due to the rising death toll in other countries, the Kenyan government mainly focused on the physical management of patients who had been diagnosed with the infection, thereby paying little attention to persons with anxiety, depression, grief and fear. One should bear in mind that most of Kenya's population receives healthcare services from the public sector. Kenyans are affected by the rising death toll, closure of schools, businesses and public places occasioned by the fast-spreading viral infections. Monitoring and assessment of the psychosocial state of people is key, especially during this pandemic, but has totally been neglected, and all public efforts mainly concentrated on the containment of the virus. The pandemic and the resulting economic recession negatively affected people's mental health and created new barriers for persons with psychosocial disorders.

2.2 The Consequences of the Restrictive Measures

The prevalence of COVID-19 increases every day across the world and Kenya is no exception. Health care systems are more and more overwhelmed with patients who are either confirmed or suspected of having the virus. Subsequently, frontline health care workers work for long and irregular hours. Constant exposure to patients with COVID-19 and increased physical and psychological pressure contribute to high levels of stress and burnout, ultimately giving rise to psychosocial issues. The first factor is the highly contagious nature of the condition, which has a high likelihood of causing severe respiratory disease and death[1]. The second factor is related to the effects of extraordinary measures adopted by the World Health Organization (WHO)[2] and governments worldwide to prevent contagion and limit outbreaks[3]. These measures resulted in loneliness due to social distancing, isolation, and stigmatisation.[4] Many Kenyans reported specific negative impacts on their psychosocial welfare, such as difficulty to sleep or eat, increased alcohol consumption or substance use, and worsening chronic illnesses, due to worry and stress over the Coronavirus.

Research shows that job loss is associated with increased depression, anxiety, distress, and low self-esteem,[5] and may lead to higher rates of substance abuse and suicide.[6] The United Nations put forth recommendations for addressing and minimising poor

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[1] See Shuai Liu, Lulu Yang, Chenxi Zhang et al., 'Online mental health services in China during the COVID-19 outbreak' (2020) 7(4) The Lancet Psychiatry. Also see Zhaorui Liu, Bing Han et al., 'Mental health status of doctors and nurses during COVID-19 epidemic in China' (2020); SSRN <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3551329> accessed 16 December 2020; Miguel Angel Martinez, 'Compounds with Therapeutic Potential against Novel Respiratory 2019 Coronavirus' (2020) 64 Antimicrobial Agents and Chemotherapy 5; <https://aac.asm.org/content/64/5/e00399-20> accessed 16 December 2020; Yu-Tao Xiang, Yuan Yang, Wen Li et al., 'Timely mental health care for the 2019 novel coronavirus outbreak is urgently needed' (2020) 7(3) The Lancet. Psychiatry 228–229, <https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(20)30046-8/fulltext> accessed 16 December 2020.

[2] See, WHO, 'Mental health and psychosocial considerations during the COVID-19 outbreak' (18 March 2020); <https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf> accessed 16 December 2020; WHO, 'Medication Errors: Technical Series on Safer Primary Care' (2016); <https://apps.who.int/iris/bitstream/handle/10665/252274/9789241511643-eng.pdf;jsessionid=FFB15C9BCA7F0CD95ADCD57642F30371?sequence=1> accessed 16 December 2020; WHO, 'Coronavirus disease 2019 (COVID-19): Situation report – 85 (2020); <https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200414-sitrep-85-covid-19.pdf?sfvrsn=7b8629bb_4> accessed 16 December 2020; WHO, 'Novel Coronavirus (2019-nCoV) Situation Report – 1' (21 January 2020); <https://www.who.int/docs/default-source/coronaviruse/situation--reports/20200121-sitrep-1-2019-ncov.pdf> accessed 16 December 2020.

[3] Mohammed A. A. Al-qaness, Ahmed A. Ewees, Hong Fan, and Mohamed Abd El Aziz, 'Optimization method for forecasting confirmed cases of COVID-19 in China' (2020) 9(3) Journal of Clinical Medicine 674.

[4] ibid.

[5] Damian Fowler, 'Unemployment during coronavirus: The psychology of job loss' *BBC Worklife* (28 March 2020); <https://www.bbc.com/worklife/article/20200327-unemployment-during-coronavirus-the-psychology-of-job-loss> accessed 16 December 2020.

[6] Mary Amanda Dew, Evelyn J. Bromet and Lili Penkower, 'Mental health effects of job loss in women' (1992) 22(3) Psychological Medicine 751; <https://www.cambridge.org/core/journals/psychological-medicine/article/abs/mental-health-effects-of-job-loss-in-women/7552307FC73EE71E894688CD230408AB> accessed 16 December 2020.

outcomes, including incorporating psychosocial support into national COVID-19 responses and increasing access to psychosocial care through telemedicine. The latter was implemented in Kenya.

However, persons with psychosocial disabilities in Kenya who did not understand the scope of the abovementioned restrictive measures, did not abide by them and were subjected to battery by the police. Quarantine became a detention measure for persons who violated government directives rather than a measure to contain the pandemic. Long-term closures of schools and childcare centres resulted in the disruption of daily routines for many parents. Psychosocial disabilities may increase among young people due to fewer opportunities to engage with peers, and so are exacerbated by the pandemic. The extreme vulnerability to coronavirus of older adults made social distancing, among other safety measures, an essential practice, thus limiting their interactions with caregivers and loved ones, leading to increased feelings of loneliness and anxiety in addition to general feelings of uncertainty and fear due to the pandemic. Persons with chronic illnesses such as chronic lung disease, asthma, serious heart conditions, and diabetes are among those with a high risk of severe illness from COVID-19, which results in feelings of fear and anxiety.

The coronavirus pandemic in Kenya worsened the already deplorable state of psychosocial support in our country. Government restrictions caused physical and mental anguish, as well as a trust deficit between public authorities and citizens, especially with the practice of acts of torture by the police in the name of enforcing government restrictions to contain the virus. Provision of psychosocial support stopped, and all attention focused on containing the pandemic, disregarding its psychosocial consequences. Persons with psychosocial disabilities and people with substance use issues pre-pandemic, and persons newly affected, will likely require psychosocial support and detoxification services. Consequently, the pandemic spotlights both existing and new barriers to accessing psychosocial services. It is also likely to have both long- and short-term implications on mental health, particularly for groups at risk of new or exacerbated psychosocial issues.

2.3 The Situation of Persons with Disabilities in Kenya Prior to the Pandemic

The state of psychosocial care in Kenya was already wanting before the pandemic. Persons with psychosocial disabilities are usually depicted as individuals in tattered, dirty clothes who would most likely be roaming around marketplaces, eating rotten fruits and vegetables; this profile could not be further from the reality of persons who require psychosocial support. Many individuals with psychosocial disabilities are well integrated in society, seemingly at peace with themselves and their environment.

However, it would be accurate to describe the general attitude towards persons with psychosocial disabilities in Kenya as one of unwillingness to be associated with them. The most excluded persons with psychosocial disabilities live in shame and isolation at Mathari National Teaching and Referral Hospital, the only government facility where residents share beds. Persons with psychosocial disabilities who require support measures are institutionalised in hospitals. They are stigmatised and subject to discrimination by their communities, which means there are no support structures to ensure their inclusion in the community. Mathari National Referral Hospital is perceived as the only well-known 'solution' for persons with psychosocial disabilities. Moreover, instead of being provided with support measures, persons with disabilities are given medication. Structurally, while hospitals in Kenya are overwhelmed by the number of persons they receive per day, the situation is worsened by a general lack of community support services for persons with psychosocial disabilities. People who live in remote areas become prisoners in their own houses, where they are locked in rooms and the only contact with the outside world consists of someone slipping in food.

The Coronavirus pandemic worsened an already tragic situation. As of December 2014, there were 3,956 government-owned health facilities that provide general health services in the country,[7] with absolutely no psychosocial services in the community, and there are no recent attempts to establish any structure that would provide inclusive services in the foreseeable future.

3. Brief Legal Analysis of the Situation: the Qualification of 'Torture'

3.1 The Standards

Torture is an act defined and prohibited by several human rights law instruments both at regional and international levels. Article 1(1) of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment and Punishment (CAT) defines torture as:

> ... any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions.

Torture is also prohibited in Article 15(1) of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) that provides for the positive obligation on States Parties to take effective action in order to prevent persons with disabilities from being subjected to torture or cruel, inhuman or degrading treatment. For an act to amount to the level of torture, certain elements need to be combined. The act has to cause severe mental or physical pain or suffering (subjective element), be carried out intentionally (intent), for a specific purpose including 'for any reason based on discrimination of any kind' (motivation, purpose) and, be committed by or with the consent/acquiescence of

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[7] Republic of Kenya Ministry of Health, 'Health Sector: Human Resources Strategy 2014-2018' (Ministry of Health 2014) 22; <https://www.health.go.ke/wp-content/uploads/2016/04/Kenya-HRH-Strategy-2014-2018.pdf#page=22> accessed 16 December 2020.

a public official (State involvement). These conditions are cumulative. The severity of the pain and suffering is an essential aspect of the material element of the crime of torture but is not sufficient. The subjectivity of the level of pain that can amount to torture is an important factor that may shift the qualification from ill-treatment to torture, or even may be employed to justify the use of force for medical or public order motives.

However, when the victim is a person with disabilities, the intention to cause harm and suffering can be implied, according to the UN Special Rapporteur on Torture (SRT). In his 2008 report, the previous rapporteur stated that, "the requirement of intent can be *effectively implied* where a person has been *discriminated against on the basis of disability*."[8] When the intention is absent, the pain inflicted cannot be qualified as torture but can still constitute ill-treatment or inhuman or degrading treatment or punishment. The SRT clarifies in the report stated above: *"Purely negligent* conduct lacks the intent required under article 1, and may constitute ill-treatment if it leads to severe pain and suffering."[9] Discrimination is another element of torture as defined by Article 1, when it is inflicted on persons with disabilities based on social norms, perception, culture and traditions. According to the SRT, this is particularly relevant in the context of medical treatment, where serious violations and discrimination "may be masked as 'good intentions' on the part of health professionals."[10] The previous SRT Juan Méndez noted that his office "made significant strides in the development of norms for the abolition of forced psychiatric interventions on the basis of disability alone as a form of torture and ill-treatment."[11] The third element is the purpose. The act has to be related to information, confession, punishment, intimidation, coercion or for any reason based on discrimination of any kind, especially with regards to persons with disabilities. Finally, the consent or acquiescence of a public official of any kind, including public health professionals, is necessary.

The African continent developed its own tools to prohibit and sanction torture. Article 5[12] of the African Charter on Human and Peoples' Rights (ACHPR) also known as the 'Banjul Charter', prohibits torture and inhuman or degrading punishment and treatment without defining it, which necessitates reference to other instruments, like Article 1 of the CAT, that include definitions and case law that clarifies it.

The African Commission on Human and Peoples' Rights (ACHPR Commission) provides guidelines and soft-law explaining the scope and application of Article 5. General Comment no 4 to the Charter, *The Right to Redress for Victims of Torture and Other Cruel, Inhuman or Degrading Punishment or Treatment* (Article 5), explains the importance of reparation and how, over and above torture's physical harm, the psychological and social dimensions of torture need to be repaired through compensating and rehabilitating the victim. Paragraphs 10 and 11 of General Comment no. 4 state:

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[8] Manfred Nowak, 'Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak' A/63/175 (28 July 2008) para 49.

[9] ibid.

[10] ibid.

[11] Juan E. Méndez, 'Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez' A/HRC/22/53 (1 February 2013) para 58.

[12] 'Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited.'

> 10. Reparation includes restitution, compensation, rehabilitation, satisfaction - including the right to the truth, and guarantees of nonrepetition... It seeks to restore the dignity, humanity and trust violated by torture and other ill-treatment. It *recognises and facilitates* the journey of coming to terms with the torture and other ill-treatment and *dealing with the consequences of trauma and other injuries*. It has *physical, psychological, social, cultural and spiritual dimensions* and helps break the cycle of violence at individual, family, collective, institutional and societal levels.
> 11. The responses required to give effect to the rights and needs of individual victims and victimised communities to determine how best to realise the right to redress must be tailored to the specific contexts in Africa...[13]

Therefore, in addition to the prohibition of the act of torture, Article 5 includes an obligation to provide reparations to victims of torture. The same logic is applied to the obligation of States Parties to take the necessary measures to respond to the needs of victims of torture and ill-treatment and offer appropriate care and support, including social support and rehabilitation. The *Resolution on Guidelines and Measures for the Prohibition and Prevention of Torture, Cruel, Inhuman or Degrading Treatment or Punishment in Africa, 'The Robben Island Guidelines'*, highlights the positive obligation of States Parties to respond to the needs of victims. Paragraph 50 of the Guidelines enumerates these measures as follows:

> 50. The obligation upon the State to offer reparation to victims exists irrespective of whether a successful criminal prosecution can or has been brought. Thus all States should ensure that all victims of torture and their dependents are: *a) Offered appropriate medical care; b) Have access to appropriate social and medical rehabilitation; c) Provided with appropriate levels of compensation and support.*[14]

The ACHPR Commission in the case of *Civil Liberties Organisation v. Nigeria*[15] found that deprivation of family visits constitutes 'inhuman treatment' and that deprivation of light, insufficient food and lack of access to medicine or medical care constitute violations of Article 5 of the Charter. In *Thomas Kwoyelo v. Uganda*, paras 203 and 204, the Commission stated that:

> the Victim was deprived of sleep during interrogations and allowed only about three hours a day for exercise and given only one meal a day... If such breach of these IHL rules were to happen, it would thus establish violation of Article 5 of the Charter particularly with respect to torture, cruel,

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[13] ACHPR Commission, *General Comment No. 4 on the African Charter on Human and Peoples' Rights: The Right to Redress for Victims of Torture and Other Cruel, Inhuman or Degrading Punishment or Treatment (Article 5)* (2017) para 10. Emphasis added.

[14] ACHPR Commission, *The Resolution on Guidelines and Measures for the Prohibition and Prevention of Torture, Cruel, Inhuman or Degrading Treatment or Punishment in Africa. The Robben Island Guidelines* (2002) para 50. Emphasis added.

[15] *Civil Liberties Organization v. Nigeria* Comm no. 129/94 (ACHPR, 22 March 1995).

> inhumane and degrading treatment. Indeed, if proved, the acts (deprivation of medical care or of sleep or absence of toilet) to which the Victim was allegedly subjected would amount at the very least to ill treatment and torture.[16]

Finally, in *Krishna Achuthan (on behalf of Aleke Banda),*[17] *Amnesty International (on behalf of Orton and Vera Chirwa),*[18] and *Amnesty International (on behalf of Orton and Vera Chinoa) v Malawi,*[19] the ACHPR Commission stated that acts of beating and torture that took place in prisons in Malawi were in contravention of the African Charter, and excessive solitary confinement, shackling within a cell, extremely poor quality food and denial of access to adequate medical care, were in contravention of Article 5.

3.2 Application of the Standards

Kenya ratified the CAT in 1997 as well as the CRPD in 2008 and the African Charter in 1992. In a pandemic context, the Kenyan government failed in its obligations as per Article 5 of the Charter as interpreted in the Robben Island Guidelines stated above. The government did not offer any appropriate medical care and focused solely on the containment of the virus, ignoring the psychological needs and distress of both persons affected with the virus and the medical staff taking care of them. There was no information dissemination on access to psychosocial or rehabilitation services, which are not available in the community in Kenya and some are only provided in the Mathari National Teaching and Referral Hospital. With the pandemic, the hospital and its staff were mobilised to take care of patients affected by the virus. The very limited psychosocial care that was available before the pandemic totally vanished. Needless to say that persons, including medical personnel, physically or psychologically affected by the pandemic were neither compensated nor supported in any way, as per the standards of the ACHPR and its interpretation of torture prohibited by Article 5 of the Charter. The Commission's jurisprudence detailed above clearly qualified deprivation of food and medication by public authorities, as well as solitary confinement as torture, while denial of contact with family members is considered 'ill-treatment'.

Persons with disabilities subjected to battery for having violated government restrictions or quarantined for the same purposes were neither compensated nor supported in overcoming the trauma they underwent. The discrimination persons with disabilities faced during the response of Kenyan authorities to the pandemic based on their disability which justified, for the law enforcement, use of excessive physical violence, in addition to unlawful detention labelled as quarantine and deprivation of decent living conditions and food, might amount to, within certain circumstances, acts of torture within the sense of Articles 1 of the CAT and 15 of the CRPD and the interpretation of the SRT in his 2008 interim report. Locking persons with disabilities in detention centres

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[16] *Thomas Kwoyelo v. Uganda* Comm no 431/12 (ACHPR Commission, 17 October 2018) paras 203 and 204.

[17] *Krishna Achuthan (on behalf of Aleke Banda) v. Malawi* Comm no 64/92 (ACHPR Commission, 10 October 1991).

[18] *Amnesty International (on behalf of Orton and Vera Chirwa) v. Malawi* Comm no 68/92 (ACHPR Commission, 2 March 1992).

[19] *Amnesty International (on behalf of Orton and Vera Chirwa) v. Malawi* Comm no 78/92 (ACHPR Commission, 6 October 1992).

or imposing quarantines on persons who are not affected for the sole reason of having a mental disability and being unable to understand government instructions without support, is discriminatory as per the standard of Article 1 of the CAT, especially in times of crisis like a pandemic.

The physical abuse inflicted upon persons with mental disabilities by Kenyan police officers for having disregarded restrictive measures cannot escape the qualification of 'intentional' given the clear intent to inflict physical pain that characterises battery. It also fulfils the requirement of the infliction to be perpetrated by a person acting in official capacity. However, the question of its being inherent to lawful sanction may be raised, even though it is easily dismissed. Indeed, a lawful sanction for having violated a curfew or an obligation to wear a mask cannot constitute physical assault. It may be arrest for a couple of hours or a fine similar to the one imposed by many countries. The extreme violence public officials in Kenya deployed against persons with disabilities who did not abide by government restrictions is characteristic of excessive use of force when evaluated against the international and regional standards described above. It cannot be justified by any rational argumentation and is simply a questionable behaviour from public authorities who applied highly invasive and aggressive measures in the name of public order and public health, many of which amount to torture as per the CAT definition.

The government of Kenya may rely on the argument of emergency, necessity to maintain public order and respond to a public health situation to defer its obligations under international law. However, Article 2(2) of the CAT dismisses that possibility by stating: "No exceptional circumstances whatsoever, whether a state of war or a threat of war, internal political instability or any other public emergency, may be invoked as a justification of torture". Understanding the burden of the COVID-19 pandemic on persons with psychosocial disabilities is crucial in guiding policies and interventions to maintain their psychological well-being. Since December 2019 when the novel Coronavirus outbreak was announced in China, the global community has been in panic mode as the disease continues to cause global suffering. Persons with psychosocial disabilities are at risk of not only contracting the disease and dying from it, but also developing psychosocial distress associated with increased exposure to stressful situations due to the pandemic.

4. Conclusion

Therefore, it is crucial, while implementing policies and measures, to take into account the psychological, and not only physical suffering, of a person or a group of persons like persons with disabilities, who would be more likely to be negatively affected by certain types of measures similar to the restrictions during the pandemic. It is also important to take into account the human factor while implementing such policies and put in place safeguards that prevent extreme behaviours like torture and ill-treatment in times of crisis, exacerbating already existing social and structural issues instead of mitigating them.

People with Disabilities Detained at the *Federico Mora* Psychiatric Institution in Guatemala are at Risk of Torture, COVID-19 Infection and Death: They must be Supported to Leave Immediately

Priscila Rodríguez Benavides

1. Introduction

People with disabilities detained in institutions across the world are subjected to torture and inhumane treatment, abuse, lack of any meaningful type of care and are forced to live in unhygienic, degrading living conditions. Institutionalisation of children with and without disabilities puts them at risk of torture and structural neglect that negatively impacts their development and may cause irreversible damage.[1] In the context of the pandemic caused by COVID-19, children and adults with disabilities in these settings are also at an especially high risk of infection and death.

Urgent steps are needed to protect people with disabilities in institutions around the world from an increased risk of torture – including the denial of lifesaving health care and protections in light of COVID-19. Advocacy groups have warned that international efforts to protect people in institutions during the pandemic could inadvertently reinforce an outdated model of institutionalisation by pouring money into segregated settings to 'increase their safety'. Instead, advocacy groups have called for an approach of "safety through inclusion" and "emergency deinstitutionalisation." The United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) has responded to this call by creating a working group on emergency deinstitutionalisation.

Under the Convention against Torture (CAT), countries are required to take action to prevent practices that amount to torture.[2] Under this obligation and the obligations that arise from the right to community living recognised by Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD), States must create community and social services that prevent torture. This includes an effort to end the institutionalisation of people with disabilities and provide alternatives and supports in the community.

States have a heightened responsibility to guarantee the rights of children and to prevent any practices that puts them at risk of torture.[3] Under this obligation, placement of children in any type of institution must be prevented as institutionalisation of children

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[1] Eric Rosenthal, 'A Mandate to End Placement of Children in Institutions and Orphanages: the Duty of Governments and Donors to Prevent Segregation and Torture' in *Protecting Children Against Torture in Detention: Global Solutions for a Global Problem* (Washington College of Law, American University and Centre for Human Rights & Humanitarian Law, 2017).

[2] ibid.

[3] Convention on the Rights of the Child (adopted on 20 November 1989, entered into force 2 September 1990) UNTS 1577.

puts them at an increased risk of torture and violates their right to grow up in a family, recognised by Article 23 of the CRPD.[4] This includes small institutions and 'group homes' which have also been deemed as a form of institutionalisation by the former UN Special Rapporteur on the Rights of Persons with Disabilities.[5] Indeed, Disability Rights International (DRI) has found that group homes function like institutions and pose the same risks of torture and abuse for children.[6]

This paper is a case study that demonstrates the reasons why – even in a developing country with limited resources – the only way to protect people detained in institutions from torture, ill-treatment, and an unnecessary risk of death, is through an approach of safety through inclusion. Efforts to 'protect' people within the context of a dangerous and segregated institution are doomed to fail.

This case study examines the situation at Guatemala's only public psychiatric facility, the *Federico Mora* National Mental Health Hospital (*Federico Mora*). People with disabilities in this institution face a risk of death as a result of the degrading and unhygienic conditions at the facility, the authorities' reckless exposure of people with disabilities to the spread of the COVID-19 virus, the failure to provide medical care, and their continued unlawful and unnecessary detention in the facility. The only way to truly guarantee the rights of and protect people with disabilities detained at Federico Mora – and in any other facility in the world – is to get them the supports they need in order to get them out immediately.

This article looks at the situation of people with disabilities detained at *Federico Mora*; provides an overview of what makes this facility so dangerous in the context of the pandemic; and argues that people with disabilities in institutions need to be urgently supported to move to the community through the provision of basic services such as housing, health care, and access to an income. This is not a matter of good will, it is an obligation under international law, particularly under the CRPD's Article 19 (right to live independently in the community).

2. Background

The *Federico Mora* National Mental Health Hospital is the only public psychiatric hospital in Guatemala; it has been labelled the "most dangerous hospital in the world" by the BBC.[7] DRI has documented the situation at this facility since 2011 and has found it to be an extremely violent and dangerous place for any person that is detained there. People with disabilities in this institution are forced to live in appalling, unhygienic and degrading conditions, face a total lack of adequate medical care and are subjected to widespread abuse – including isolation, prolonged physical restraints, physical and sexual abuse, and rape – that amounts to inhuman and degrading treatment, and torture.

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[4] Eric Rosenthal (n 1).

[5] Catalina Devandas Aguilar served as UN Special Rapporteur on the Rights of Persons with Disabilities from 2014 until August 2020.

[6] Disability Rights International, 'A Dead End for Children: Bulgaria's Group Homes' (2019); <https://www.driadvocacy.org/wp-content/uploads/Bulgaria-final-web.pdf> accessed 10 December 2020.

[7] BBC documentary, 'Inside 'world's most dangerous' hospital in Guatemala' (2014); <https://www.youtube.com/watch?v=bEAYETfqA5M> accessed 10 December 2020.

In 2012, DRI successfully requested the Inter-American Commission on Human Rights (IACHR) to grant precautionary measures (MC-370-12) in favour of the people detained at *Federico Mora*. The IACHR ordered the State of Guatemala to take urgent measures to address the violence, abuse and degrading conditions at the facility. However, in its last monitoring visit in February 2020, DRI found that the conditions and abuses that gave rise to the precautionary measures continue to persist.[8]

People with disabilities at this institution are particularly at risk of infection and death from COVID-19. As of August 2020, at least half of the people with disabilities detained at the institution had tested positive for COVID-19, three had died, and 31 people with disabilities were unaccounted for.[9] Given the close quarters and lack of opportunity to socially isolate at the facility, even more detainees could become infected. DRI has also received reports that people with disabilities at the facility have been locked in the residential wards and are not allowed out for medical care. If the necessary actions are not immediately taken to get the people out, a large number of people could die.

According to the institution's own staff, three quarters of the population at the institution could leave today if they had access to housing in the community.[10] This means that they are detained because they have nowhere else to go – and not because of a purported medical necessity. DRI has also found that procedures for detention of all people with disabilities lack protections required by international law. These detentions were, therefore, both unnecessary and illegal before the immediate crisis caused by COVID-19. Given the immediate threats to health and life of all detainees caused by COVID-19, DRI is calling for an end to the arbitrary detention and immediate provision of housing and support in the community for *Federico Mora* detainees in accordance with Article 19 of the CRPD.

Under the CRPD, signed and ratified by the State of Guatemala, the State must take immediate action to guarantee the life, safety and protection of *Federico Mora* patients in the face of the COVID-19 pandemic. Consistent with the recommendation of UN Human High Commissioner for Human Rights that governments "discharge and release persons with disabilities from institutions and promptly ensure provision of support in the community," Guatemala must transfer people now detained at *Federico Mora* out of the facility. They should be moved into a safe and supported community setting; these measures will require the urgent provision of community-based housing and the necessary support and health services in the community to be able to do so.

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[8] Given the new imminent threat that patients are facing at *Federico Mora* due to the presence of COVID-19 cases at the institution, DRI has requested the IACHR to extend the precautionary measures and request the Government of Guatemala to take urgent actions to protect the life of this population.

[9] Guatemala, 'Report of the State of Guatemala to the Inter-American Commission on Human Rights' (24 September 2020). During DRI's last monitoring visit, there were 321 people with disabilities detained at the institution. In its report to the IACHR, the State of Guatemala reported that there were 2 90 patients at the facility in September 2020.

[10] The rest could leave as well but would need more supports than just housing. IACHR, 'Situation of Human Rights in Guatemala' (2017) para. 468; <https://www.oas.org/en/iachr/reports/pdfs/Guatemala2017-en.pdf> accessed 10 December 2020.

3. Risk of Abuse, Infection and Death in Closed Settings like *Federico Mora*

According to the World Health Organization (WHO), COVID-19 is a type of infectious disease within the Coronavirus category; such diseases "cause respiratory infections ranging from the common cold to more severe diseases such as Middle East Respiratory Syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS)."[11] The WHO has noted that "[p]eople with disabilities may be at greater risk of contracting COVID-19."[12] Persons with disabilities detained in residential institutions are at an even greater risk of contracting the virus. In this regard, former UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas, has stated that:

> The situation of people with disabilities who are in institutions, psychiatric facilities, and prisons is particularly serious, due to the risk of contamination and the absence of external supervision, a situation that is aggravated by the use of states of emergency due to the health crisis.[13]

The IACHR, in its Press Release 71/20, noted that people with disabilities who are deprived of liberty in psychiatric hospitals "face a situation of special risk of contagion from COVID-19."[14] The Commission stressed that:

> based on the information documented through its various monitoring mechanisms, the Commission has observed that these centres of deprivation of liberty would be characterised by overcrowding, lack of adequate hygiene, negligent medical care, and inadequate food. In this regard, the Commission recalls that States have a special duty to protect persons with disabilities who are deprived of liberty.[15]

Available information on the spread of COVID-19 confirms that people in residential institutions, and particularly institutionalised people with disabilities, are at increased risk of contracting the virus and dying. In the United States, the country with the highest number of confirmed cases in the region and the world, it has been confirmed that persons with disabilities in residential institutions have a much higher death rate than the general population. A recent study found that residents with intellectual

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[11] WHO, 'Q&A on coronaviruses (COVID-19)' (12 October 2020); <https://www.who.int/news-room/q-a-detail/q-a-coronaviruses> accessed 10 December 2020.

[12] WHO, 'Disability considerations during the COVID-19 outbreak' (2020) 1; <https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1> accessed 10 December 2020.

[13] UN News, 'Las personas con discapacidad, en riesgo por el coronavirus' (17 March 2020); <https://news.un.org/es/story/2020/03/1471282> accessed 10 December 2020.

[14] IACHR, 'En el contexto de la pandemia COVID-19, la CIDH llama a los Estados a garantizar los derechos de las personas con discapacidad' (8 April 2020); http://www.oas.org/es/cidh/prensa/comunicados/2020/071.asp> accessed 10 December 2020. *See also*, IACHR, 'Pandemia y Derechos Humanos en las Américas' 7 (2020); <http://www.oas.org/es/cidh/decisiones/pdf/Resolucion-1-20-es.pdf> accessed 10 December 2020.

[15] IACHR, 'En el contexto...' (n 14).

disabilities "of group homes and similar facilities in New York City and surrounding areas were 5.34 times more likely than the general population to develop Covid-19 and 4.86 times more likely to die from it."[16]

The simple fact of living in a congregated environment puts anyone at risk. In Europe, a study carried out by the International Long-term Care Policy Network (ILPN) and the Care Policy and Evaluation Centre (CPEC) at the London School of Economics, and Political Science (LSE)[17] found that about half of the deaths that had occurred in the European Union from the coronavirus happened in residential institutions. According to this study, "[s]napshot data from varying official sources shows that in Italy, Spain, France, Ireland and Belgium, between 42% and 57% of deaths from the virus have been happening in [residential] homes."[18] In France, the percentage of deaths among residents of care homes have ranged from 39.2% to 49.4%. In Belgium, as of 16 April, 69.3% of COVID-19 related deaths had occurred in care homes. In the case of Spain, it was found that COVID-19 infection "affects all the care residences for older people, but also other institutionalised groups with some disability."[19]

The IACHR has called on States to "adapt the conditions of detention of persons deprived of liberty, particularly concerning food, health, sanitation, and quarantine measures to prevent intramural contagion of COVID-19, guaranteeing in particular that all units have medical attention."[20] However, since 2012, DRI has found inhumane and degrading conditions at *Federico Mora*, including overcrowding, unhygienic conditions, lack of medical care and inadequate food.

In 2017, in a report entitled *The Situation of Human Rights in Guatemala*, the IACHR found that the prevailing situation at *Federico Mora* "reflects the lack of protection of persons with disabilities in Guatemala,"[21] and mentioned the unsanitary and unhealthy conditions that prevail at the institution, "fostering infectious diseases and posing an immediate threat to the health and lives of the patients."[22] All of these are factors that persist to date at the institution and increase the risks of contracting COVID-19.[23]

In its last monitoring visit to the facility in February 2020, DRI observed barefoot patients inside and outside the wards, with dirty and inadequate clothing. There were also people eating on the floor. DRI visited very early in the morning when the weather

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[16] Danny Hakim, "It's Hit Our Front Door': Homes for the Disabled See a Surge of Covid-19' *The New York Times* (8 April 2020); <https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html?referringSource=articleShare> accessed 10 December 2020.

[17] Adelina Comas-Herrera, Joseba Zalakaín et al., 'Mortality associated with COVID-19 outbreaks in care homes: early international evidence' International Long-term Care Policy Network (12 April 2020); <https://ltccovid.org/2020/04/12/mortality-associated-with-covid-19-outbreaks-in-care-homes-early-international-evidence/?subscribe=success#blog_subscription-3> accessed 10 December 2020.

[18] Robert Booth, 'Half of coronavirus deaths happen in care homes, data from EU suggests' *The Guardian* (13 April 2020); <https://www.theguardian.com/world/2020/apr/13/half-of-coronavirus-deaths-happen-in-care-homes-data-from-eu-suggests> accessed 10 December 2020.

[19] Oriol Güell, 'Residencias y hospitales concentran los nuevos contagios por coronavirus' *El País* (11 April 2020); <https://elpais.com/sociedad/2020-04-10/residencias-de-mayores-y-hospitales-acaparan-la-mayoria-de-nuevos-contagios-del-coronavirus.html> accessed 10 December 2020.

[20] IACHR, 'Pandemia y Derechos Humanos...' (n 14) para. 47.

[21] IACHR (n 14).

[22] ibid.

[23] ibid.

was cool and noted that people were not wearing sweaters or anything to cover themselves, which can also increase the likelihood of contracting respiratory illnesses. DRI observed two patients defecating in the yards of the hospital.

4. People with Disabilities Must be Supported to Leave Institutions Immediately

In the midst of the pandemic, the UN High Commissioner for Human Rights has said that, in the case of people with disabilities living in institutions, the first action that States must carry out is to "[d]ischarge and release persons with disabilities from institutions and promptly ensure provision of support in the community through family and/or informal networks, and fund support services by public or private service providers."[24]

In its Press Release 71/20, the IACHR stated:

> Regarding persons with disabilities detained in psychiatric institutions and social assistance centres, States must intensify efforts to develop the creation and establishment of community services that meet the needs of patients in the community, and with it, avoid institutionalising these people.[25]

Specifically, in the case of *Federico Mora*, the IACHR observed that, in order to fully guarantee the life and integrity of patients detained in this institution, the measures that the State takes should be aimed at creating services in the community.[26] The IACHR lamented the lack of action by Guatemala to invest in getting people out of the institutions and stated that "[t]his situation is particularly worrisome considering that most of them continue living at the institution because no support is available to them in the community."[27] These supports consist of access to basic services that include housing, food and medical treatment.

The IACHR recommended that the State "guarantee community living for these persons, by creating and establishing community-based services. For this purpose, the Commission urges the State to adopt, among others, the following measures: a) expeditiously define a strategy for the deinstitutionalisation of persons with disabilities, with a timeline, sufficient resources and specific evaluation measures."[28]

Almost three years after the IACHR determined that the State must create services in the community so that institutionalised persons can be reintegrated into the community, the State has not taken the necessary actions. The result is that, during this health crisis, there

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[24] United Nations Office of the High Commissioner for Human Rights, 'COVID-19 and the Rights of Persons with Disabilities: Guidance' (29 April 2020) 3; <https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf> accessed 10 December 2020.

[25] IACHR, 'En el contexto...' (n 14).

[26] IACHR (n 10) para. 468.

[27] "The IACHR notes that according to the evaluation conducted in 2013 by independent psychiatric and medical staff of the hospital itself, approximately 75% of the patients (without including those in conflict with the law), did not need to remain at the institutions 'for psychiatric reasons,' and could 'easily' become integrated into the community, if there were outpatient services available to them." IACHR (n 10) para. 469.

[28] ibid.

are hundreds of people who are detained for the simple fact of having a disability and having nowhere to go due to the lack of alternatives in the community. This fact, which in itself is a violation of their human rights and puts their integrity at risk, at this time also presents a mortal risk. By being detained with patients and staff who have contracted COVID-19, the entire *Federico Mora* population is at risk of acquiring this virus, and death.

It is not enough that the State isolates patients and infected staff. In order to protect the life of people detained at *Federico Mora*, the State must establish "community services that meet the needs of patients in the community"[29] and guarantee that the people who are currently detained in *Federico Mora* have immediate access to these services, including medical care, outside of the institution. Expert organisations on disability and mental health issues have recommended that to cope with the pandemic, and "to facilitate a decrease in the psychiatric inpatient population, the federal government, states, and localities should increase their support of community providers of outpatient mental health treatment."[30]

5. Conclusion

Under the CRPD, people with disabilities cannot be involuntarily locked up based on their disability, and this includes people with disabilities at *Federico Mora*. Any person with a disability who is detained against their will for no criminal purpose and who wishes to leave an institutional setting should be allowed to do so. Every person leaving the facility should be immediately provided a place to live in the community where they will be safe and receive the basic living supports they require to take care of themselves. People should be provided food, medical care, and in-home personal assistant services necessary to live independently.

States, and specifically Guatemala, must create an emergency plan to create support services for people in institutions so that they can live safely and independently in the community. States must also guarantee immediate access to medical care. This should include social isolation, testing of patients and staff, effective quarantining, removal of residents or staff who test positive for COVID-19, and having full access to the necessary medical services in a community setting. States must also provide accessible information about safety, access to medical care, and advocacy support in the community.[31] Individual support and advocacy to obtain protection, care, and support services is also essential.

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[29] ibid.

[30] Judge David L., 'During the Pandemic, States and Localities Must Decrease the Number of Individuals In Psychiatric Hospitals, By Reducing Admissions and Accelerating Discharges' Bazelon Center for Mental Health Law (2020); <https://docplayer.net/189389888-July-7-press-packet.html> accessed 10 December 2020. *See also*, International Disability Alliance, 'Toward a Disability-Inclusive COVID19 Response: 10 recommendations from the International Disability Alliance' (19 March 2020); <http://www.internationaldisabilityalliance.org/sites/default/files/ida_recommendations_for_disability-inclusive_covid19_response_final.pdf> accessed 10 December 2020.

[31] Former UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, stated that "[p]ublic advice campaigns and information from national health authorities must be made available to the public in sign language and accessible means, modes and formats, including accessible digital technology, captioning, relay services, text messages, easy-to-read and plain language." United Nations Office of the High Commissioner for Human Rights, 'COVID-19: Who is protecting the people with disabilities? – UN rights expert' (17 March 2020); <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25725> accessed 10 December 2020.

Litigating Emergency De-institutionalisation as Torture

János Fiala-Butora

Challenging institutionalisation as torture has a long tradition in human rights advocacy, for obvious reasons – but with not so obvious consequences. Freedom from torture is a cornerstone of the international human rights protection system, and a finding of torture brings with it a serious moral condemnation. But litigators do not simply want to make a point by winning before courts. They are looking for remedies which help individual victims and those affected similarly, by transforming policies. They want change on the ground, not declarations. This chapter looks at the advantages and disadvantages of relying on the torture framework to challenge institutionalisation of persons with disabilities at the time of the COVID-19 pandemic.

1. Institutionalisation as Torture in International Law

Human rights organisations monitoring institutions of persons with disabilities have often described institutionalisation through the lens of ill-treatment.[1] They have reported on practices which have already been found to constitute elements of torture in other settings, such as prisons or asylum centres.[2] The reports established that dilapidated physical conditions, overcrowding, lack of privacy, lack of meaningful activities, poor access to healthcare, forced treatment, restraints, physical and sexual abuse are widespread in institutions for persons with disabilities.[3]

Despite the fact that the conditions in institutions are often worse than in prisons, it took a long time for international courts to recognise institutions as places of ill-treatment. This finally happened with the judgment of the European Court of Human Rights (European Court) in *Stanev v. Bulgaria*, which reviewed the conditions in the Pastra home, arguably the worst social care institution in Bulgaria.[4] However, this important precedent did not lead to a surge of successful litigation. It was followed by *Stankov v. Bulgaria*, but no other cases since then.[5] The European Court found other types of violations connected to institutions but did not classify these as ill-treatment.[6]

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[1] János Fiala-Butora, 'Disabling Torture: the Obligation to Investigate Ill-treatment of Persons with Disabilities' (2013) 45 Columbia Human Rights Law Review 214.

[2] For examples of how the UN Human Rights Committee (HRC) and the Committee against Torture (CAT) addressed some aspects of torture affecting persons with disabilities, such as restraints and forced sterilizations, see Phil Fennel, 'Article 15: Protection against Torture and Cruel or Inhuman or Degrading Treatment or Punishment' in Ilias Bantekas, Michael Stein, and Dimitris Anastasiou (eds.), *Commentary on the UN Convention on the Rights of Persons with Disabilities* (Oxford University Press, Oxford, 2018), 426-465.

[3] Janet E. Lord, 'Shared Understanding or Consensus-Masked Disagreement? The Anti-Torture Framework in the Convention on the Rights of Persons with Disabilities' (2010) 33 Loy. L.A. Int'l & Comp. L. Rev. 27.

[4] *Stanev v. Bulgaria* App no 36760/06 (ECtHR, 17 January 2012).

[5] *Stankov v. Bulgaria* App no 25820/07 (ECtHR, 17 March 2015).

[6] For example *D.D. v. Lithuania* App no 13469/06 (ECtHR, 14 February 2012).

During the negotiations on the adoption of the Convention on the Rights of Persons with Disabilities (CRPD), disability advocates tried not simply to abolish certain practices harming persons with disabilities but to have them declared as torture. Involuntary treatment or the use of restraints are good examples. The text of the CRPD is not sufficiently clear on these practices, therefore advocacy continues since its adoption as well.

Institutionalisation was also argued to constitute torture. However, the Committee on the Rights of Persons with Disabilities (CRPD Committee) has not considered conditions in institutions as torture under Article 15 of the CRPD, only as abuse under Article 16. It found a violation of Article 16 on the account of poor living conditions,[7] insufficient nutrition,[8] neglect,[9] and violence in institutions.[10] None of these problems warranted an examination of institutionalisation *as* torture in the CRPD Committee's view.

2. The Advantages and Disadvantages of the Torture Framework

There are obvious advantages to recognising a practice not simply as a human rights violation, but specifically as torture or another form of ill-treatment. Torture is the most serious violation of the human right to personal integrity and dignity.[11] It is an absolute right which permits no derogations or limitations.[12] Resource constraints can justify the limitations of other rights, but not freedom from torture.[13] The state is obliged to provide redress to victims of torture, including by prosecuting perpetrators.[14]

Freedom from torture does not permit taking into account competing interests. If something is classified as torture, its use must not simply be limited or curtailed, but discontinued without debate. Not recognising involuntary treatment or restraints as torture would legitimise these coercive practices and provide wide discretion to states on how and to what extent to police their use. It would invite counter-interests and counterarguments, both legitimate and illegitimate, to be balanced against the rights of victims, and used as excuses to retain illicit practices.

In the long run, the "correct" use of coercion, as opposed to its "abuse", would be a question determined individually, which domestic authorities are better placed to review than international bodies. This particularly empowers medical professionals, as they have

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[7] CRPD Committee, Concluding Observations: Serbia, UN Doc CRPD/C/SRB/CO/1 (23 May 2016) para 31.

[8] CRPD Committee, Concluding Observations: Latvia, UN Doc CRPD/C/LVA/CO/1 (10 October 2017) para 28.

[9] CRPD Committee, Concluding Observations: Armenia, UN Doc CRPD/C/ARM/CO/1 (8 May 2017) para 27, CRPD Committee, Concluding Observations: Republic of Moldova, UN Doc CRPD/C/MDA/CO/1 (18 May 2017) para 32.

[10] CRPD Committee, Concluding Observations: Lithuania, UN Doc CRPD/C/LTU/CO/1 (11 May 2016) para 32.

[11] Manfred Nowak, 'Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak' A/63/175 (28 July 2008) para 50.

[12] Juan E. Méndez, 'Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez' A/HRC/22/53 (1 February 2013) para 82.

[13] ibid., para. 83.

[14] CRPD Committee, Concluding Observations: Slovenia, UN Doc CRPD/C/SVN/CO/1 (5 March 2018) para 26; CRPD Committee, Concluding Observations: Montenegro, UN Doc CRPD/C/MNE/CO/1 (22 September 2017) para 31; CRPD Committee, Concluding Observations: Serbia, UN Doc CRPD/C/SRB/CO/1 (23 May 2016) para 28.

the most direct first-hand information about each case, and their determinations necessarily involve the application of medical norms. It is easy to see why many victims would find this solution unacceptable. After all, in terms of power relations, it is not that different to what we had before the CRPD. It has led to significant suffering and abuses, which the CRPD aims to overcome, not preserve.

Freedom from torture is also an immediate obligation. That feature is particularly appealing to advocates who are no doubt frustrated by the slow progress in implementing rights which are subject to progressive realisation. The standards of progressive realisation are unclear, and thus difficult to review by international bodies. As such, progressive realisation has often been used by states as an excuse to delay honouring their obligations flowing from human rights treaties, although such excuses are unjustifiable.

Similar arguments have also been used in defence of institutionalisation. It has been explicitly recognised as a human rights violation some time ago, at least since the adoption of the CRPD, whose article 19 protects the right to independent living. States parties have been required to implement de-institutionalisation plans. Yet progress has often been unsatisfactory. States are both delaying the transformation of social services and are also questioning the goal itself by referring to competing interests, be those of staff, the community, the government providing funds, or residents of institutions who allegedly “like it” inside institutions and want to stay within them.

In the face of such resistance, framing institutionalisation as torture is undeniably quite appealing. It attaches a particular moral condemnation to the practice, which might be more difficult for states to own up to. It would send a clear message that transferring residents to the community is not up for debate, and that it cannot wait. However, portraying a practice as ill-treatment also has its disadvantages. Arguing and proving all attributes of torture can be problematic in the case of coercive practices, including institutionalisation.

Only those practices which achieve a particular level of severity can be classified as ill-treatment, and only the most severe of these can be considered torture. This might be too high a threshold to reach with institutionalisation alone. Some practices, some instances of institutional experience could no doubt meet the threshold, but declaring the practice of institutionalisation as ill-treatment per se might be too big of a step for courts to take, condemning this strategy to perpetual unsuccessfulness.

Since the prohibition of torture is absolute, no exceptions can be accepted under it. This means that if institutionalisation is identified as torture, the only legitimate goal would be to eliminate it immediately instead of gradually reducing its occurrence. This is contrary to what states are currently trying to achieve, and what many consider a laudable goal.[15] We must recognise that the need for immediate transformation of social services does have legitimate constraints, such as the need for resource allocations, staff

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[15] Brian O’Donoghue, ‘Coercion: an understudied issue in mental health’ (2017) 34 Irish Journal of Psychological Medicine 222; Bernadette McSherry & Ian Freckelton (Eds.) *Coercive care: Rights, law and policy* (New York, NY: Routledge, 2013).

training, rehabilitation of clients, etc. The absolute nature of the prohibition of torture does not provide space for such considerations to be taken into account. It is simply not a framework suited for balancing competing interests in a complicated policy framework. Torture requires states to take an immediate all or nothing approach, and if they are presented with that choice, states might be very tempted to opt for "nothing" if they see the alternative as impossible to implement.

States Parties are bound by the CRPD, but they have possibilities not to comply with a norm which they consider impossible to implement. They can resort to wilful non-compliance. If there is consensus among them, it will be hard for the CRPD Committee to overcome their resistance, especially since it is the states that are parties to the CRPD, and their subsequent agreements and practices are a source of its interpretation.[16] They can also create exceptions by reclassifying some forms of institutionalisation as not-torture. This seems impossible due to the absolute nature of prohibition of torture, but in fact it is not without precedent in international law. A very similar approach was adopted by the European Court in the *Herczegfalvy* case,[17] where the prolonged use of restraints, which would be otherwise considered ill-treatment, was considered not to constitute ill-treatment if medically necessary. Medical necessity might not be accepted as a justification under the CRPD, but other similar similar justifications could be. States would only need to find a disability-neutral way of phrasing the conditions for permissible institutionalisation, and thereby remove them from the CRPD's scope. This neutrality would only be formal, although the impact would still disproportionally affect persons with disabilities. Nevertheless, it might be seen by many as a viable option if the alternative is portrayed as seeking the impossible. Interestingly, such a disability-neutral approach formally avoiding violation of the CRPD has already been proposed under other articles of the CRPD.[18]

Also, it seems to be clear that notwithstanding differences in pace across states, de-institutionalisation will take some time. At least for a temporary period, institutions are here to stay, and some persons will be moved to the community faster than others.[19] The absolute prohibition of torture is not the best framework to deal with such temporary situations. Due to its absolute nature, it requires immediate implementation.[20] States cannot legitimately experiment with safeguards and regulation in order to monitor and limit the practices which are recognised as torture.[21] This means that at least for a temporary period, victims staying in institutions would enjoy less protection in a torture framework than they might in a different one.

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[16] Article 31(3) b) and c) of the Vienna Convention on the Law of Treaties (VCLT), 1155 U.N.T.S. 331 (27 January 1980).

[17] *Herczegfalvy v. Austria* App no 10533/83 (ECtHR, 24 September 1992).

[18] Wayne Martin, Sabine Michalowsky, Timo Jütten, Matthew Burch, 'Achieving CRPD Compliance, Is the Mental Capacity Act of England and Wales Compatible with the UN CRPD? If not, what next?' An Essex Autonomy Project Position Paper (22 September 2014).

[19] Peter Bartlett and Marianne Schulze, 'Urgently awaiting implementation: The right to be free from exploitation, violence and abuse in Article 16 of the Convention on the Rights of Persons with Disabilities (CRPD)' (2017) 53 International Journal of Law and Psychiatry 9.

[20] CRPD Committee, Concluding Observations: Slovakia, UN Doc CRPD/C/SVK/CO/1 (17 May 2016) para 46.

[21] Juan E. Méndez (n 12) para 89 b).

The CRPD Committee has recognised similar temporary adjustments to otherwise applicable rules under other articles. For example, under Article 14, while it requires the abolition of involuntary hospitalisation, "until as such time as these provisions have been amended", it has required Latvia to implement court review of hospitalisations.[22] Similarly, while the Committee rejects the practice of sheltered workshops, it required Hong Kong to raise the daily allowance for persons in sheltered workshops to protect them from exploitation under Article 16.[23] The Committee and States Parties do not enjoy such flexibility under the torture framework, which might leave victims worse off, at least in the short run.

Lastly, the torture framework might also not offer the most effective remedies to victims. I have argued elsewhere that criminal law is not an appropriate solution for many victims with disabilities suffering from ill-treatment in institutions due to, among others, accessibility problems, the violations' systemic nature, and criminal law's focus on the perpetrator rather than the victim.[24] In the case of institutionalisation, the picture is even more complicated. Who is the perpetrator in this case? Is a criminal sanction such as prison time for a nurse or social care worker an adequate response? Maybe there is a legitimate point to make about how and under what conditions it might be, but it is very difficult to imagine how members of the care professions would participate in such a discussion. And without their involvement, it is hard to develop alternative services. Other articles of the CRPD are more suited to introduce a different range of remedies that aim at reducing unwanted practices, such as educational, administrative and social measures.[25]

3. How does the Pandemic Change the Calculus?

The above general reasons apply in usual times. However, the global COVID-19 pandemic creates extraordinary circumstances. How does it change the relevance of the torture framework in respect of institutionalisation?

Other chapters in this volume have shown that a direct correlation between institutionalisation and death from COVID-19 have emerged in several countries. The consequences of contracting the virus go beyond a high chance of dying. Many patients describe the illness as very painful, no doubt reaching the required level of severity to constitute ill-treatment. To be sure, it is not the authorities causing pain to the victims – but by keeping them in settings where they have a very high chance of contracting the virus, they are knowingly exposing them to a high risk of suffering. This goes contrary to their obligations, which is to protect persons from suffering.

Those who might not get infected are also suffering the psychological effects of being exposed to the high risk of undergoing a severe illness and dying from it. This psychological suffering is especially pronounced in the case of residents of institutions

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[22] CRPD Committee, Concluding Observations: Latvia, UN Doc CRPD/C/LVA/CO/1 (10 October 2017) para 25. (b).

[23] CRPD Committee, Concluding Observations: China, UN Doc CRPD/C/CHN/CO/1 (15 October 2012) para 68.

[24] János Fiala-Butora (n 1).

[25] Bartlett and Schulze (n 19) 7.

where the virus has already been detected. Not being able to take the only safe option and leave the place, they are essentially trapped in a room with death itself. Even if they survive, psychological suffering is inevitable. The European Court has recognised the concept of psychological torture and would likely be able to understand it in these circumstances as well.[26]

An important consequence of the pandemic is that care staff are no longer the ones causing the suffering – they are also the victims of it. This is very different than involuntary treatment and restraints, where they take on the roles of perpetrators. They might be much more supportive of disability advocates' arguments describing the situation as torture, and many might share the goal as well: release residents to settings where they are safer.

4. Conclusion – How to Choose the Best Way to Proceed

Litigators are not restricted to rely only on freedom from torture when challenging institutionalisation. They can use other provisions of international law in addition to the prohibition of torture. The right to independent living and the right to private life are amenable to review and oversee the different questions related to effective implementation of deinstitutionalisation strategies, such as resource constraints, priority settings, and temporary situations. Torture is not an effective framework for these tasks, and the pandemic has not changed that.

However, the pandemic has changed some other aspects of the relevance of the torture framework and has made it a more effective avenue to argue for urgent solutions. If freedom from torture had some attractive features before, it has become an almost unavoidable element in an effective strategy to respond to the pandemic.

As explained above, the pandemic helps us overcome some of the shortcomings of the torture framework which would otherwise caution us against resorting to it. With regard to the others, it depends on the precise remedies asked for. Governments might argue that emergency de-institutionalisation requires difficult policy decisions to be made which are resource- and time-intensive. That is true. However, coming up with a clear emergency plan with reasonable timelines is neither resource- nor time-intensive: it can be done in a short time, and can rely on the existing administrative capacities of the state. If litigators asked for this remedy, courts could be sympathetic, and governments could have a hard time explaining why they are unwilling to comply with such a request.

Governments might argue that an obligation to de-institutionalise is not new, it existed before the pandemic as well. That argument could be reversed by litigators. The fact that governments had such an obligation before the pandemic means that they should have closed the institutions already. The fact they have not done that has exposed and subjected a large number of persons with disabilities to excruciating physical and mental suffering. They did not intend that, nobody did, but it nevertheless happened because of their failure to act. And it will happen again, unless they finally honour their obligations.

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[26] Irfan Neziroglu, 'A Comparative Analysis of Mental and Psychological Suffering as Torture, Inhuman or Degrading Treatment or Punishment under International Human Rights Treaty Law' (2007) 4 Essex Hum. Rts. Rev. 1.

The pandemic is proof that institutionalisation as a cause of ill-treatment is no longer a speculation, a fanciful argument: it has become provable fact. Overcoming it has become more important and urgent than ever. When the next pandemic comes (because it will come, the question is only when), governments should no longer be able to argue that they did not know the impacts on persons with disabilities in institutions. They do now.

Legal Redress for Persons with Disabilities in Pandemic Situation

Chidi Oguamanam

1. Introduction

In ordinary times, persons with disabilities are the most vulnerable. They struggle to function through diverse states of inequality in relation to others. As their *raisons d'ètre*, human rights legal frameworks represent a pathway for mitigation and redress against the barriers that saddle persons with disabilities. Those barriers are animated by multifaceted forms of discrimination, including those issuing on the basis of gender, race, sexual orientation, circumstances of birth, age, and disabilities, to name the few. Human rights are the law's arsenal for safeguarding the dignity of all human persons. They are the law's guarantee that everyone is entitled to realise their own optimal potential in all circumstances of lived experience, across all stages of life.

There are well-established international and national legal and administrative channels for holding states and non-state actors accountable to their positive and negative obligations[1] to protect the human rights of citizens. Those have developed recently to incorporate the evolving context of disability rights as human rights.[2] To better understand persons living with disabilities, specifically in pandemic situations, and to mull strategies for legal redress, there are two starting points for deconstruction of disabilities: (1) to recognise that disability is a complex concept; and (2) that in a pandemic situation, disabilities engage multifaceted intersectionalities.

In framing redress for persons with disabilities in a pandemic, it is important to recognise that disabilities are not satisfactorily captured in instruments dealing directly with the concept. The 2007 Convention on the Rights of Persons with Disabilities (CRPD)[3] outlines *armed conflict, humanitarian emergencies* and *natural disaster* as paradigmatic contexts for persons with disabilities, triggering state obligations.[4] Emergencies often result in the disruption of public and social services, as well as loss of jobs, income evaporation and other economic activities which are sources of real and potential threats to persons with disabilities. Even though a pandemic could result in a humanitarian emergency, it is not clear that pandemic is recognise as a stand-alone factor that escalates the plights of persons with disabilities. It is about time.

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[1] See Manwendra Tiwari, 'Critique of Jurisdictional Case Against Constitutional Socio-Economic Rights' (2017) 9 *RMLNLU*; <https://bit.ly/2Up9pE2> accessed 10 November 2020.

[2] See Mona Paré, 'The Convention on the Rights of Persons with Disabilities: Its Contribution to the Development of International Human Rights Law' (2019) 11:17 *Revista ESMAT* 209-230.

[3] UN General Assembly, *Convention on the Rights of Persons with Disabilities*, 13 December 2006, A/RES/61/106, Annex I.

[4] Article 11.

2. Intersectionality Imperative and the Dynamics of Disabilities in Pandemic

The CRPD also defines persons with disabilities in an open-ended manner. They include "those who have long-term physical, mental, intellectual or sensory impairments which in *interaction with various barriers* may hinder their full and effective participation on equal basis with others".[5]

Despite the definition's flexible orientation, there is apparent bias for disabilities as a "long-term" condition, running the risk of neglecting the fluid and inchoate nature of circumstances under which disabilities arise. For example, a range of mental health issues, including anxiety, depression, suicidal thoughts are associated with COVID-19 pandemic.[6] Psychiatric patients are 65% predisposed to being diagnosed with COVID-19.[7] Women are 27% more likely than men to suffer COVID-19 associated psychological distress.[8] In addition to psychosocial disability, the contagion has capacity to transition its victim into state of physical disabilities.[9] The psychosocial toll of COVID-19 and its disruptive effects on a person's mental health varies in terms of short- or long-term impact. Physicians are only beginning to unravel the experiences of COVID-19 "long haulers".[10] While some endure COVID-19 pandemic-induced temporal states of mental and, consequently, psychosocial disabilities; others' experiences take a long-term dimension.

The reference to "interaction with various barriers" is a recognition of intersectionality.[11] That sensitivity is evident in WHO's more pragmatic approach to disability as arising "from the interaction between a person's health condition or impairment and *multitude of influencing factors* in their environment".[12] Every case of disability reproduces interconnected and overlapping sets of social, economic, and political contexts in which an individual is situated. Those contexts are domains of discrimination and therefore should serve as real sites of interest for seeking human rights redress for persons with disabilities. One of the gaping holes in human rights is the tendency to narrowly focus on victims without integrating an intersectional understanding of their vulnerabilities. In almost one year of COVID-19, everyone is a witness to how those vulnerabilities have radically escalated.

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[5] Article 1, para 2 (emphasis added).

[6] See Maxime Taquet et al, 'Bidirectional Association between Covid-19 and Psychiatric Disorder: Retrospective Cohort Study of 62,354 COVID-19 Cases in the USA' Lancet Psychiatry (9 November 2020).

[7] ibid.

[8] CARE.CA, 'She Told Us So: Filling the Data Gap to Build Back Equal' (2020); <https://bit.ly/2UiJo9h> accessed 17 December 2020 (reporting that 27% more women likely to report mental health challenges associated with COVID-19).

[9] For example, Broadway star, Nick Cordero, had his right leg amputated owing to complication from coronavirus. See <https://bit.ly/35vZHWI> accessed 11 December 2020. Late Cordero's experience is only one of many limb-threatening blood clots now associated with coronavirus as a source of physical and psychosocial disability.

[10] See Michael Marshall, 'The Lasting Misery of Coronavirus Long-Haulers' Nature (14 September 2020).

[11] For a seminal elaboration of intersectionality, see Kimberle Crenshaw, 'Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics (1989) U. Ch. Leg. F. 139-168.

[12] WHO, 'Disability'; <https://bit.ly/36CmnDZ> accessed 17 December 2020 (emphasis added).

Also important are diversities and subtleties of disabilities, diversities of intersectionality of persons with disabilities, as well as the diversities of contexts for discriminations. Every person living with disabilities is peculiar; and their relationship with society involves complex intersections. Imagine a pregnant diabetic woman, with physical and mental disabilities. She is a member of a culturally inferior social class (caste) and is mobility-constrained. She is a citizen of a poor country living below the poverty line and is contending with the burden of surviving a pandemic with no social safety net. Imagine a similar scenario for a member of historically marginalised groups, albeit that they are citizens of a rich country. These persons have to interact with these "multitude of influencing factors" or barriers before they are able to access or leverage any pandemic relief. Yet, the pandemic actually aggravates their ability to navigate these barriers.

3. COVID-19 and the Escalation of Global Health Inequality

Since the outbreak of the COVID-19 pandemic, health inequalities at global and national levels have never been starker.[13] Developed countries report lop-sided statistics of fatalities along racial and poverty lines, reinforcing prevailing sites of discrimination now aggravated by the pandemic. Lop-sided statics implicate institutional long-term care settings, where a majority of the victims are persons living with various forms of disability[14] and where ageism is magnified.[15] In many cases, these victims are targets of enhanced mandatory confinements and surveillance, physical, and sexual assaults by co-inmates or even care providers. Long-term care residents – most of whom are on the disability spectrum – as well persons in institutional, carceral, correctional and rehabilitative centres, are victims of system failures and derelictions symptomatic of human rights deficits now aggravated by the pandemic.[16] Most states are in deficit of their human rights obligations in regard to how they have handled vulnerable populations. These torturous experiences stoke the perennial tension between disability, mental health, and human rights.

As necessary as they are, the spotlight on long-term care centres should not be at the expense of the precarious situations of other persons with disabilities at individual, communal, and other confined informal institutional settings in developed and developing countries.[17] In many developed countries, the prevalent ideological disposition to individualism and nuclear families predispose persons living with disabilities to falling through the cracks in pandemic emergencies.

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[13] Philip Schellekens, Diego M. Sourrvouille, 'COVID-19 Mortality in Rich and Poor Countries: A Tale of Two Pandemics' World Bank Policy Research Working Paper #9260 (June 2020); <https://bit.ly/38KrlB9> accessed 17 December 2020.

[14] Niel Gandal, et al, 'Long-Term Care Facilities as a Risk Factor to COVID-19: Evidence from European Countries and U.S. States'; SSRN <https://bit.ly/3npANhB> accessed 10 November 2020.

[15] Annika T. Larsson and Håkan Jönson, 'Ageism and Rights of Older People' in Liat Ayalon and Clemens Tesch-Romer (eds), *Contemporary Perspectives on Ageism* (Springer, Cham: 2018) 269-382.

[16] Trudo Lemmens and Roxanne Mytituik, 'Disability Rights Concerns and Clinical Triage Protocol Development During the COVID-19 Pandemic' (2020) 40:4 *Health Law in Canada* 103-112.

[17] See Lawrence O. Gostin and Lance Gable, 'The Human Rights of Persons with Mental Disabilities: A Global Perspective on the Application of Human Rights Principles to Mental Health' (2004) 63:40 Maryland Law Review 20-121.

4. A Snapshot of African Contextual Reality

Regardless of a pandemic or other emergency, the dynamic of vulnerability for persons with disabilities in Africa and most of the developing world is radically different.[18] Institutional long-term care for the elderly is not the norm. Neither is there standardised regimen for treating persons suffering from mental disabilities, especially in unorthodox settings. Family sizes are larger and extended, and not limited to conjugal family. Incidentally, they serve as safety nets. The agencies of the family and the community are informal structures to support and enhance the protection of persons with disabilities. However, embedded in those informal frameworks are cultural practices and stigmatisations against persons with disabilities, resulting in inhuman and degrading treatments outside state superintendence.[19] For instance, persons with mental and psychosocial disability are often physically restrained, physically and mentally abused under aspects of traditional medicinal rituals such as exorcism. Without social safety nets, governments abdicate the care of vulnerable citizens in the hands of largely informal agents that often operate under unregulated mandatory confinements and other forms of torturous or ill treatment.

5. Human Rights Abuses

In the above contexts, ad hoc pandemic management ordinances disproportionately impact persons living with disability. Not only are they rendered vulnerable to human rights-eroding treatment protocols. The correlation of these experiences to degrading treatment or even torture opens the opportunity for creative legal framing and redress for persons with disability in a pandemic situation. The 1984 Convention against Torture and Other Cruel, Inhuman and Degrading Treatment or Punishment[20] criminalises acts that occasion severe pain or suffering in their physical or mental dimensions.[21] Even though the Convention's bias is in the context of extracting incriminating evidence, three points are redemptive for its application in human rights abuses of persons with disabilities in pandemic: (1) the Convention covers 'other' undefined categories of inhumane or degrading treatment or punishment; (2) by implication, it includes negative human rights obligations such as omissions and negligent conduct of states; and (3) it defers to international and national legislation that takes a more liberal application of torture.[22]

6. Conclusion

Framing human rights redress for persons with disabilities in a pandemic requires leveraging the evolving nature of disability rights and the pathology of COVID-19.[23] There is a need to recognise intersectionality to accommodate the individual experience and

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[18] Martin R. Rupiya, 'The Impact of the COVID-19 Pandemic on the Elderly in Africa' Accord (7 June 2020); <https://bit.ly/3noc50V> accessed 12 November 2020.

[19] See Magnus Mfoafo-M'Carthy and Marie-Antoinette Sossou, 'Stigmatization, Discrimination, and Social Exclusion of the Mentally Ill' (2017) 2 J. Human Rights & Social Work 128-133.

[20] UN General Assembly, Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 10 December 1984, United Nations, Treaty Series, vol. 1465, p. 85.

[21] Article 1.

[22] Article 1(1).

[23] The Disabilities and Torture Conventions continue to develop progressive understanding of disability and torture in ways that enrich human rights jurisprudence with substantive prospects for the current pandemic.

global health inequities. Beyond the law, professional training guidelines and ad hoc ordinances and ethical standards need to proactively mainstream disability sensitivity and cultural safety in service delivery in a pandemic. States must continuously blend welfare and rights-based approaches driven by accurate data[24] in order to reach persons with disabilities in a pandemic situation. Affirmative entitlement to dignified mental health treatment and the dynamic nature of psychosocial disruptions needs to be reinforced. Law is only one tool to change the experience of persons with disability. Awareness raising, strategic litigation and advocacy are crucial to pursue change in social orientation.[25] The association of the COVID-19 pandemic with mental and psychosocial disabilities clearly opens new opportunities for progressive elaboration of disabilities and the scope of inhuman and degrading treatment in a complementary approach to human rights and mental health.

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[24] Most developing countries can use communal structures to generate critical data.

[25] See Chaitanya Laddha, 'Rights of Persons with Disability: A Human Rights Approach' (29 March 2016); SSRN <https://bit.ly/38FxTBj> accessed 11 November 2020.

Denial of Essential Services: Lessons from Malawi and Latvia in Providing Care for Persons with Psychosocial Disabilities during a Pandemic

Thandiwe Mkandawire, Ieva Leimane-Veldmeijere and Felicia Mburu

1. Introduction

“If disability is one of the great human rights challenges of this century, then within this, psychosocial disability remains one of the most challenging and misunderstood areas of disability”[1] – said Paul Deany, Disability Rights Fund Program Officer at the 9th Session of the Conference of States Parties to the CRPD. Although there is increased recognition internationally of the economic costs associated with mental health issues, increasing awareness of the specific forms of human rights violations faced by people with psychosocial disabilities, and other related issues, such as poor health outcomes and higher prevalence of premature death, mental health remains an under-prioritised and neglected area of public policy and service provision in many countries. Further, the discourse around mental health sometimes reduces the debate to one of health care policy, failing to engage with the broader social and structural barriers faced by people with psychosocial disabilities in exercising their rights. As Deany points out: “Fundamental issues such as housing, support, jobs, education, voting, and political and legal rights are seldom considered.”[2]

People with psychosocial disabilities frequently report experiencing serious human rights violations in the community and within conventional health care systems, at times being subjected to severe restrictions on personal liberty and integrity. The use of seclusion, restraint and forced medication, for example, are commonplace within institutional psychiatric provision in countries around the world, and in certain instances these practices amount to torture or cruel, inhuman or degrading treatment or punishment.[3] In many countries, people with psychosocial disabilities continue to experience the impacts of an overwhelmingly medical model approach to their treatment and care, with limited focus on improving respect for human rights and quality of life. Building more psychiatric hospitals is often posited as a primary form of service for persons with

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[1] Paul Deany, ‘Psychosocial Disability: one of the most misunderstood areas of disability’ (15 June 2016); <https://disabilityrightsfund.org/our-impact/insights/psychosocial-disability/> accessed 18 December 2020.

[2] ibid.

[3] See, for example: Mental Disability Advocacy Centre (MDAC) and Mental Health Uganda (MHU), ‘Psychiatric hospitals in Uganda: A human rights investigation’ (2015); <http://www.mdac.org/sites/mdac.info/files/psyciatric_hospitals_in_uganda_human_rights_investigation.pdf> accessed 18 December 2020; MDAC, ‘Cage beds and coercion in Czech psychiatric hospitals’ (2014); <http://www.mdac.org/sites/mdac.info/files/cagebed_web_en_20140624.pdf> accessed 18 December 2020; and ‘Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture’s 2013 Thematic Report’ (Washington College of Law, American University and Centre for Human Rights & Humanitarian Law, 2013); <http://antitorture.org/wp-content/uploads/2014/03/PDF_Torture_in_Healthcare_Publication.pdf> accessed 18 December 2020.

psychosocial disabilities, rather than improving access to a range of rights-based services in the community. Even in respect of conventional psychiatric provision, access to voluntary treatment is extremely low, particularly in low- and middle-income countries, and there is a lack of sustainable investment to improve the availability and accessibility of mental health services at the community level.[4]

As such, few countries guarantee the range of preventive, supportive and other individualised services necessary for people with psychosocial disabilities to have their rights respect. The COVID-19 pandemic simply exacerbates these structural barriers, and in some cases has caused significant harm. Studies indicate that COVID-19 and its direct impacts (bereavement, isolation, loss of income) will have profound impacts on the wellbeing of people worldwide, and this is also true among people with psychosocial disabilities.[5] This also affects people who provide support and personal assistance. In the United States, for example, it has been reported that unpaid caregivers for adults were not being supported and that this has had a significant impact on their mental health and wellbeing,[6] meaning that even informal and family-based support structures were undergoing serious strains. The COVID-19 Disability Rights Monitor (DRM), which was designed to monitor the impact of COVID-19 on the rights of persons with disabilities,[7] equally reported increased levels of stress and anxiety caused by denial or complete stoppage of essential services.[8]

Despite this evidence, only 17% of countries worldwide report that they have included a mental health and psychosocial support component within their overall COVID-19 response and recovery initiatives.[9] In its guidelines to African countries, the African Commission on Human and Peoples' Rights called on member states to prioritise humane and inclusive responses premised on the principles of equality and non-discrimination,[10] yet very few have considered the possible implications of massive and strict lockdowns on people with psychosocial disabilities.

This paper argues that certain public services, such as voluntary, preventive mental health care, peer support groups and personal assistance services may be essential for persons with psychosocial disabilities and that states are under obligations to mitigate potential and foreseeable types of harm. Indeed, in certain circumstances, the withdrawal of support and other services could leave individuals at risk of serious harm and trauma, potentially arising to ill-treatment and/or torture.

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[4] World Health Organization (WHO), 'Special Initiative for Mental Health (2019 – 2023): Universal Health Coverage for Mental Health' (2019).

[5] United for Global Mental Health, 'The Impact of COVID-19 on Global Mental Health: A Brief' (2020).

[6] Centers for Disease Control and Prevention, 'Morbidity and Mortality Weekly Report. Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic – United States, June 24–30, 2020' (2020) 69:2 Morbidity and Mortality Weekly Report 1049.

[7] More about the DRM, see https://covid-drm.org/.

[8] Ciara Siobhan Brennan et al., 'Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor' (2020) 31; <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf> accessed 18 December 2020.

[9] WHO, 'COVID-19 disrupting mental health services in most countries, WHO survey' (5 October 2020); <https://www.who.int/news/item/05-10-2020-covid-19-disrupting-mental-health-services-in-most-countries-who-survey> accessed 11 December 2020.

[10] Solomon Ayele Dersso, 'Press Statement on human rights based effective response to the novel COVID-19 virus in Africa' (24 March 2020); 31 <https://www.achpr.org/pressrelease/detail?id=483> accessed 18 December 2020.

2. Essential Services

For the purpose of this article, ‘essential services’ refers to those services required by and provided to persons with psychosocial disabilities, the interruption of which could endanger their lives, health or personal safety. It is beyond the scope of this article to set out a comprehensive and definitive list of such services, but they are likely to include a range of social, health and other services which enable people with psychosocial disabilities to keep themselves safe and to prevent them experiencing severe harm. This can include guarantees of being able to access trusted individuals who support with decision-making; advice, counselling, and other forms of alternative care; community-based personal assistance, mutual aid and supporter schemes; and voluntary mental health care and treatment. Receiving adequate levels of nutrition is also essential, as is the ability to access general and specialist medicines, particularly for those who need consistent supply of therapeutic treatments.

From this vantage point, a variety and range of services can be argued to be essential, even within the context of the pandemic. Further, as part of the obligations of state to protect the rights and liberties of persons with psychosocial disabilities, any decisions to suspend, hinder or completely halt services must be carefully and rigorously assessed by decision-makers, particularly where such decisions could have severe or even mortal consequences. For some individuals, it may be crucially important for them to maintain regular access to mental health care professional. For others, the ability to attend support groups or self-help groups is critical. There is also a growing recognition of the need for community-based mental health care services to be available to support people experiencing stress, anxiety, depression, and potentially to prevent or respond to specific situations of emergency or crisis.

Comprehensible and reliable information is also important, ensuring that all citizens, including persons with psychosocial disabilities, are aware of and know how to access essential services. As well as those services mentioned above, it is important that policy makers and service providers take action to tackle the isolation and stigma which affect so many persons with psychosocial disabilities, and to prevent and remedy the high levels of abuse and exploitation that they report experiencing, a situation which appears to have increased in the context of lockdowns and scarce supplies.[11]

In summary, essential are those services which enable persons with psychosocial disabilities to keep themselves safe, particularly during a pandemic. These must be person-centred and recovery oriented, and they play a crucial role in preventing people with psychosocial disabilities from experiencing severe harm which can foreseeably be predicted.

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[11] COVID-19 Disability Rights Monitor (COVID-19 DRM) Coordinating Group, ‘COVID-19 Disability Rights Monitor calls on governments to ensure access to food, medication and essential supplies for person with disabilities’ (17 September 2020); <https://covid-drm.org/en/statements/covid-19-disability-rights-monitor-calls-on-governments-to-ensure-access-to-food-medication-and-essential-supplies-for-persons-with-disabilities accessed 18 December 2020>; and COVID-19 DRM Coordinating Group, ‘COVID-19 Disability Rights Monitor (DRM) calls for an end to police violence and abuse against persons with disabilities and their family members’ (4 August 2020); <https://covid-drm.org/en/statements/covid-19-disability-rights-monitor-drm-calls-for-an-end-to-police-violence-and-abuse-against-persons-with-disabilities-and-their-family-members> accessed 18 December 2020.

3. Lessons from Malawi: Closure of Essential Services Reflects Stigma and Discrimination

In Malawi, people often associate psychosocial disability with alcohol and substance use and spiritual causes, all of which are perceived negatively and allude towards the purported moral failings of an individual. 1% of Malawi's health care budget is allocated to mental health care,[12] compared to 5% in high income countries,[13] and existing mental health services in Malawi are characterised by centralised in-patient psychiatric facilities (Zomba Mental Hospital, St. John of God Hospitaller Services) and lack of available data.[14] Limited community-based care and support predate the pandemic,[15] and civil society organisations such as Mental Health Users and Carers Association (MeHUCA) attempt to fill this gap through providing mental health and psychosocial support to persons with psychosocial disabilities, particularly through running peer support groups.

Because of closed borders, Malawi has experienced an extended period of inadequate medical supplies and those mental health service users who were taking medications have been asked to switch to available drugs that they do not want, or have been asked to access private pharmacies that they cannot afford. Furthermore, community-based mental health care has been suspended due to COVID-19 measures.

According to the respondents from Malawi to the survey of the COVID-19 Disability Rights Monitor, there was no access to information about COVID-19 for persons with disabilities living in remote and rural areas,[16] and children with disabilities were excluded from remote learning because they did not have access to technology.[17]

COVID-19 measures disrupted MeHUCA's activities as well, and peer support group face-to-face meetings were forced to shift to tele-group support. This allowed for continued communication among group members, however limitations on social interaction, a lack of medicine and the loss of businesses has had a significant impact on the mental health of persons with psychosocial disabilities, with reports of relapses and deaths. In addition, community mental health forums have reported an increase in alcohol and substance use among young people.[18]

Finally, in the context of Malawi, stigma against persons with psychosocial disabilities remains widespread, leading to feelings of shame, blame, secrecy, isolation, social exclusion and discrimination. Stigma is a major reason that persons with psychosocial

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[12] Michael Udedi, 'Improving access to Mental Health services in Malawi' Ministry of Health Policy Brief (July 2016); <https://www.researchgate.net/publication/306065762_Improving_access_to_mental_health_services_in_Malawi> accessed 11 December 2020.

[13] WHO, 'Mental Health Atlas 2011' (WHO, 2011).

[14] ibid. Malawi Country Profile.

[15] Brian S. Barnett, Veronica Kusunzi, Lucy Magola, Christina P. C. Borba, Michael Udedi, Kazione Kulisewa & Mina C. Hosseinipour, 'Description of the inpatient population and care received at a psychiatric unit in Lilongwe, Malawi' (2018) 11:4 International Journal of Culture and Mental Health 574-582.

[16] Ciara Siobhan Brennan et al. (n 8) 30.

[17] ibid. 36.

[18] MeHUCA, Mental Health Matters Project Report.

disabilities choose not to access treatment and supports that may be essential to prevent serious consequences, including suicides. The result of this is apathy and a lack of accountability in the provision of essential services.

4. Lessons from Latvia: Provision of Supported Decision-Making

Supported decision-making is recognised in Article 12 of the UN Convention on the Rights of Persons with Disabilities. RC ZELDA[19] has been providing supported decision-making (SDM) services to around 80 persons with psychosocial disabilities and/or intellectual disabilities. Support in decision-making is offered in all main areas of life – support can be provided around various issues including legal matters, finding a place to live, helping to address human rights violations and seeking redress, planning and personal budgeting, as well as helping to resolve issues with banks or creditors. Other types of assistance in decision-making concern simple daily matters, assistance to access health or social care services, and helping people to communicate with medical professionals.

The main priority of a supporter is to facilitate the wishes, will and preferences of supported person. The SDM service is based on a person-centred thinking and planning approach,[20] employing the following sequence of stages in the process of supported decision-making: ascertaining the supported person's wishes, will and preferences, obtaining and providing information, examining options, decision-making, implementation and evaluation. It is important to emphasise that supporters not only provide support in making decisions, but also in the implementation stage of the decisions made by persons receiving support. Supporters never make decisions on behalf of the person with intellectual or psychosocial disability, rather they help the person to understand the circumstances and consequences of his/her actions in order to make his/her own decisions.

Latvia instituted a three-month long state of emergency which meant service providers simply locked the doors and were not available. For several persons, the SDM service and maintaining connections with their supporters was crucial, particularly around visiting medical specialists or simply to get up-to-date and accessible information regarding COVID-19, and associated rules and restrictions on accessing public services. While some service providers, such as RC ZELDA, were able to provide services remotely (e.g. using phone, video chats, WhatsApp or Skype), the lockdown measures still caused a disruption of service and mental anguish for service recipients. Also, all types of group activities, where supporters would meet with several persons that they support, were either discontinued or had to be replaced by online groups. However, not all the

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[19] The Resource Centre for People with Mental Disability "ZELDA" (RC ZELDA) is Latvian NGO, which aims to promote de-institutionalisation and development of community based mental health care services for people with psychosocial and/or intellectual disabilities through research, monitoring of observance of human rights, legal advocacy and activities of informing and educating the public. More on RC ZELDA see http://www.zelda.org.lv/en.

[20] Person-centred thinking and planning are a set of structured methods designed to help supporters to ensure quality of life from the supported person's perspective. These methods can be used to assist the supported person think about what is important in his or her life right now in their lives and what the person wants to achieve in the future. See more at: http://helensandersonassociates.co.uk/.

supported persons were familiar with internet or smart phones. Some supported persons did not want any visiting and that was respected. But also, when needed, supporters visited supported persons at home and they also went out together regularly for walks.

5. Conclusion

Many countries in their constitutions have provisions that set out which human rights are regarded as fundamental, and which can be restricted, and upon what grounds, for instance in order to protect the rights of other people, to protect the democratic structure of the State, or to ensure public health and safety. In the context of COVID-19, such emergency restrictions should be tailored to ensure that they do not directly or indirectly discriminate against persons with psychosocial disabilities; and, further, must operate on a clear understanding that certain services necessary for persons with psychosocial disabilities should be protected and understood as 'essential', particularly where they enable persons with psychosocial disabilities to protect themselves from severe anguish, harm and suffering. These consequences are reasonably foreseeable, preventable, and arguably come within the obligations of states to prevent ill-treatment, including on the basis of disability.

Various international and regional human rights organisations and bodies have begun pointing out that states must not misuse emergency laws in a way which discriminates in purpose or effect against persons with psychosocial disabilities. A human rights-based response to the pandemic requires that any restrictions be implemented in a non-discriminatory manner, and there must be strong accountability structures in place to prevent discrimination. Shutting down essential services required by persons with psychosocial disabilities should be assessed in this light. It flows from this that states must guarantee the continuity of a range of essential services for people with psychosocial disabilities, including during the pandemic, to avoid unnecessary harm.

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