Opinion Piece

Affirming Radical Equality in the Context of COVID-19: Human Rights of Older People and People with Disabilities

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Abstract

This paper discusses the impact of COVID-19 on older people and people with disabilities. It draws attention to the violations of their human rights in the context of COVID-19 which in turn reveal the hierarchical social order of our society. Although statistics show higher deaths of older people in regard to COVID-19, these numbers co-exist with rampant discrimination towards these groups with underlying messaging that their lives are dispensable. The paper highlights violations at different levels—discursive, ethical, and everyday—and shows how they are underpinned by ageism and disablism which stereotype older people and people with disabilities with prejudicial messaging and actions by states and societal actors. At the same time, the paper also highlights the value of human rights discourses and instruments which are mobilized by the disability movement and groups upholding the rights of older people, to question these rights infringements in the context of COVID-19. The politics of these groups which call for principled equality and inclusion of older people and people with disabilities in times of COVID-19 exhibit a much-needed disruption of our social order, an undertaking that needs to be continued in COVID-19 times and after.

Keywords: ageism; care homes; COVID-19; disabilities; human rights violations; older people

COVID-19 has revealed some of the existing fault lines in our society, which can be seen by the painful effects of the pandemic on certain social groups. Existing ageism and disablism, which refer to prejudices, stereotyping and practices of discrimination against people because they are older or have an impairment, have led to the violation of human rights of older people and people with disabilities in many parts of the world in responses to COVID-19. Evidence shows higher death statistics among older people—suggesting that they are at a higher risk of death, particularly in the case of those with co-morbidities

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(WHO 2020). However, it is important to note that these statistics indicating higher risks coexist with many forms of discrimination against these groups, including those living in care homes, mainly occupied by older people and people with disabilities. For example, while accounting for deaths of these groups in care/nursing homes remains fragmented, horrific anecdotal stories about the plight of older people living and dying in them have been reported from different parts of the world, such as reports about corpses of elderly people abandoned in care homes which are now being investigated by the Spanish authorities (Keeley 2020; Connolly 2020). The reports of very high numbers of deaths in care homes across different countries in Europe and in the USA have also raised questions about risks posed to their residents due to issues such as lack of protective equipment and inadequate standards and guidance regarding care (Connolly 2020). In the early weeks of the pandemic, deaths in care homes were not counted in the daily government briefings about deaths in the UK by the Cabinet Office, which suggested that the plight of older people and people with disabilities who formed the bulk of the people in these places was treated as invisible and they were not counted as full citizens (The Guardian 2020). In their detailed submission to the UK Parliament’s Joint Committee on Human Rights, Lewis and Kirby (2020) argue that the UK government has not followed the standards of the European Convention on Human Rights and the UN Convention on the Rights of Persons with Disabilities in their protection of people in care homes, which mainly house the elderly or people with disabilities.

The violations in the context of COVID-19 are indicative of the struggle of these groups for the affirmation of their human rights. Human rights are mobilized by excluded groups in order to be recognized as a part of the community on the basis of freedom and equality. In this regard, Rancière contends ‘the Rights of Man are the rights of those who have not the rights that they have and have the rights that they have not’ (2004: 302). That is, to the extent that the excluded act as though they have human rights (by mobilizing them), they can be said to have those rights that they still don’t have. The disability movement and movement for older people’s rights have in the past and in the present contexts of violations evoked universal human rights as a pivot to ending their discrimination. The Convention on the Rights of Persons with Disabilities, adopted in 2006, is a significant milestone achieved by the disability movement in that direction. Yet despite high levels of ratification of that convention, not many countries have developed national laws and interventions aligned with the spirit and obligations of the Convention. In relation to older people, led by organizations such as HelpAge International and several organizations working for older people’s well-being, a global convention for older people’s rights has made some progress, but still has a long way to go towards becoming a reality (Herro 2019; Mégret 2011).

With this background, we discuss the effects of COVID-19 on these two groups, the rights infringements experienced by them, and the counter-voices against these infringements at three levels: discursive, ethical and everyday. In order to develop this analysis, we

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1 France, for example, reported that almost one-third of all coronavirus deaths have been of residents in care homes (Connolly 2020). The UK also reported a very high number of deaths in care homes: by the end of May, of 38,161 dead, about 16,000 people had died in care homes (Booth 2020a).

2 Some progress can be seen, for example, in the adoption of the regional Inter-American Convention on the Rights of Older Persons, which has now been ratified by several Latin American countries.
briefly discuss the processes of making the discursive categories ‘disabled’ and ‘older’ subjects in the last few decades.

**Making of the ‘disabled’ and ‘older’ subjects and their effects**

Building upon Foucault’s work, disability theorization has drawn on the concept of bio-power to show how in the last two centuries the contemporary disabled subject has emerged through a wide apparatus of institutions: asylums, disability assessments, telethons, prenatal diagnosis and other practices (Tremain 2005). These technologies have ‘identified’, classified some people as social anomalies, and objectified them as ‘feeble minded’, ‘retarded’, ‘handicapped’, or ‘impaired,’ thereby normalizing these categories. The contemporary disability movement has questioned the medical hegemony in constituting ‘disabled subjects’ and for ignoring the oppressive social and physical structures that constrain them (Oliver 2009; Barnes 1991; Barton 1996). Also termed the ‘social model of disability’, its proponents strongly argue for modification of the social environment by removing barriers, rather than the rehabilitation of individuals through ‘special institutions’, a practice which continues in many societies to the present day. More recently, critical disability theorization has argued that the medical categories of ‘impairments’ themselves are discursively constructed categories against the idea of ‘normal’ bodies, which highlight deficits that need to be corrected (Allen 2005). The idea of correcting deficient bodies has historically traumatic consequences leading to the eugenics movement, which continues today in many societies as well (Johnson 2003). The COVID-19 discourse also highlights similar and terrible assumptions made about ‘weak’ and ‘older’ bodies as dispensable objects—as will be discussed below. The ‘older subjects’ have in the last few decades emerged through regimes of social welfare policies and practices in different countries including care homes, pensions and benefits, with underlying contradictory narratives of stigma, dependency, risk, and respect of these groups (Biggs and Powell 2001; Mégret 2011). The current older generation is also sometimes referred to as ‘babyboomers’, as the years following the Second World War had seen an increase in fertility rates (see Oxford English Dictionary definition), and this vocabulary has been reused in new and negative ways in the time of COVID-19, an issue highlighted below.

**Infringements of rights and counter-voices against such infringements**

**Discursive**

An analysis of the discourse about COVID-19 and its effects shows that it contributes to the further stereotyping of people with disabilities and older people as less useful and valued, and more as a burden to society, with an underlying message that it is acceptable for these groups to die. The trending of the meme ‘babyboomer remover’ (see Sparks 2020) and YouTube videos (see Under Subsidence) have called COVID-19 a blessing in disguise for removing the babyboomers who are old, and the weak. Such messages when hosted by sites with thousands of subscribers get normalized in society. Placards held by anti-lockdown protesters in the USA with the slogan ‘sacrifice the weak’ also highlight similar sentiments (McCloskey 2020). Championing against the lockdown, the suggestion of the Lieutenant-Governor of Texas, Dan Patrick, that older people (including himself) would
rather die than let COVID-19 harm the US economy also underlines a belief that older lives are more dispensable than others (Beckett 2020). In an interview, Ukraine’s former health minister said that people over 64 are already corpses and the government should focus its COVID-19 efforts on people ‘who are still alive’ (Human Rights Watch 2020). Disability activists have highlighted how, under COVID-19, ‘health rationing’ and advice on who gets to live under crisis conditions are biased against people with disabilities when ideas of ‘social usefulness’ underpin such decisions against the larger stereotype about people with disabilities being ‘parasites’ of society (Ladau 2020; Pfeiffer 2020). This brings us to issues of ethics, namely the principles that are guiding decision-making processes in the context of COVID-19, and its effects on older people and people with disabilities.

Ethics

The domain of ethics is about moral principles that guide our actions. COVID-19 has highlighted the prejudice informing policy decision-making being applied to older people and people with disabilities in many country settings. COVID-19 has led to the World Health Organization (WHO), as well as different governments, coming out with regulatory advice including that of social distancing, social isolation and lockdowns. We have been told that this advice is based on the medical evidence. Specific and separate advice has been given for older people as they are considered to be a high-risk group. For example self-isolation by older people has been advised by the WHO, with the implementation of this advice in many countries by severe legal restrictions on older people’s freedom of movement, leading to a lot of hardship and mental anxiety among these groups (Human Rights Watch 2020). In the UK there has been a debate about bringing in a law to ensure that those over 70 years old are in self-isolation with curbs on their movement outside the place where they live. At the time of writing, the new guidance notification by the UK government issued on 31 May 2020 (UK Government 2020) has relaxed the lockdown—allowing people to go out as many times a day as they want and meet up to six people outside their households while keeping a certain distance from each other. However, those over 70 years old are en masse advised to stay at home and to minimize any contact with people who are not members of their household. Even if one concedes that these are well-meaning advisories, they do not appear to be aligned with the basic moral ideas of ‘respect’ and ‘recognizing voice’ of all groups equally in any democratic decision-making. When these groups are en masse and singularly targeted for restrictions on their movements, then it is a case of medical-based advice trumping the rights of individuals in arbitrary ways. Medical ethics (for example, even in cases of palliative care) always use individual medical assessments (which can be controversial) to come to a reasoned judgment about treatment for that particular case or individual. The issue here is the use of medical-based criteria applied to a whole section of the population simply because they are older. If the state were to seriously implement an age-based criterion with the medical criteria, then it would have to examine every single person, for example above the age of 60 or 70, to see whether that particular person needed to be isolated based on some agreed medical standard. Just because the state does not have the capacity to examine and assess everyone with regard to these issues, the state cannot lock down all people above a particular age. It would be far better policy to uphold the dignity of individual persons in this group by letting individuals decide on how they want to practise the social isolation advisory. Baroness Ros Altmann rightly calls the current discussions on bringing in such a blanket law in the UK ageist and
discriminatory, and contends that decisions should not be based solely on medical advice but rather allied with the ‘principles of individual freedoms, informed choices and recognition of individual rights’ (Altmann 2020).

More generally, COVID-19 has seen a problematic use of en masse decisions about how to treat people living in care homes. In the UK, care home residents in Hove, East Sussex, and Wales have had ‘do not attempt resuscitation’ (DNAR) notices applied to them en masse, which have now been branded as unacceptable by NHS (National Health Service) regulators. In normal times, such decisions are always made on an individual basis by the doctors and communicated to the individuals in their care, after a medical examination and opinion that they may not be able to cope with intrusive resuscitation. The en masse notices however send very different signals and are now being looked into by the Care Quality Commission, the independent regulator of health and adult social care in England (Booth 2020b; Elder-Woodward 2020).

Everyday
The International Disability Alliance (IDA) has been documenting the rampant everyday discrimination against people with disabilities in the context of COVID-19 in different country settings and has been leading a campaign for rights of people with disabilities (see IDA 2020a). They highlight, for example, how in Romania, after a COVID-19 outbreak in the care home of Sasca Mică, while medical staff were hospitalized, people with disabilities were quarantined in a separate building, suggesting a difference in treatment given to each of these groups (IDA 2020c).

While WHO and governments are developing guidance on protection against COVID-19, people with disabilities and older people have raised issues about inaccessibility of guidance and information, despite the Convention on the Rights of People with Disabilities mandating inclusive forms of communication. Such lack of information in particular has led to anxieties, fear and also tragic outcomes, as in the case of a deaf youth in Uganda who was not aware of the curfew, and who went out and was shot in the leg as he was not able to hear the police warnings (IDA 2020b). Amnesty International’s report on Cox’s Bazar camp, Bangladesh, highlights the dangers of the lack of basic information for Rohingya older refugees living in a camp with poor sanitation (Amnesty International 2020). Documenting the experiences of older people, HelpAge International (2020) and groups working with older people have called for non-discrimination and the protection of the human rights of older people in all COVID-19 responses.

Older people and people with disabilities face deep challenges of insecure livelihoods, hunger, and living an everyday life of dignity in many low- and medium-income countries. Reports from India suggests that distress calls to helplines from elderly have increased in the time of COVID-19, with most asking for support in regard to food and medicines, among other things. Older people are worried about their future and dying alone (Agarwal 2020). Mental health issues are reportedly prevalent among those who have been forced to live in isolation with no recourse to health facilities. Many have not been able to access medicines or health facilities although they need them as a matter of urgency (see testimonies and experiences, IDA 2020a; HelpAge International 2020). Organizations campaigning against disablism and ageism continue to highlight the manifold rights violations against these groups and insist that any ‘new normal’ after COVID-19 must include these groups and be based on consultations with them (Elder-Woodward 2020).
Affirming radical equality of rights in the times of COVID-19 and after

COVID-19 and its effects have seen infringements of rights both of older people and of people with disabilities, as well as counter-voices questioning these rights violations. The rights violations during the time of COVID-19 reflect the hierarchical social order we live in, where some lives are considered less worthy. Yet they also show that invocation of human rights is invaluable in such times, as it enables these groups to further their politics of inclusion, and the right to equality and dignity that all human beings are entitled to. For Rancière (2010), it is the radical ‘politics’ of the excluded subject which ruptures the social hierarchies in a social polity.

There are three aspects of the equality–inclusion politics of these groups that I highlight in conclusion: agency, recognition, and accessibility, which are at odds with our current dominant social order. Implicated in agency is the right to be consulted, and to make decisions about areas that affect their lives, whether in COVID-19 times or after. Recognition implies a stand that insists that nobody is ‘abnormal’, or rather that there is no dominant standpoint from which normality of the body can be evaluated, that every person’s life is worthy, and cannot be treated as dispensable in times of COVID-19 or after. Accessibility contests the current design and formation of spaces, places and communication systems that exclude these groups from participating in private and public arenas or accessing information and other entitlements such as health. The demand for radical equality insists on the principled equality of people with disabilities and older people here and now, and a radical restructuring of the current social order. Politics during COVID-19 and after is necessary for such social order disruption.

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