

## TIME FOR A UN CONVENTION ON THE RIGHTS OF OLDER PERSONS

How the COVID-19 pandemic has shown the need to protect our rights in older age

#### ABOUT THIS PAPER

This discussion paper has been developed by an informal group brought together on their own initiative to respond to the call of the Chair of the UN Open-ended Working Group on Ageing (OEWG) inviting stakeholders to contribute ideas and proposals on the possible elements of a new international instrument. The group comprises a small number of representatives of NGOs and experts with the immediate goal to provide input that will support the work of civil society as well as help frame the discussion at the OEWG. As a self-appointed group, it cannot reflect the diversity of the stakeholders involved in the OEWG whose opinions need to inform the next steps. Neither do its views necessarily build on the broad and consensual positions of the organisations that its members represent.

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#### INTRODUCTION

The lessons learned from the COVID-19 pandemic provide a unique opportunity to rethink our societies, including how we age and the attention, recognition and support we give each other when we are older.

COVID-19 has shown just how badly things go wrong when our human rights are not protected.

Older persons have been hit particularly hard by the virus itself but the failure to protect their rights in the response has led to unnecessary deaths, deterioration of cognitive, mental and physical health, unmet health and other support needs, increased poverty, discrimination, abuse, vilification and stigmatisation.

Just as COVID-19 recognises no borders, so too the world needs a legal foundation to ensure this tragedy never happens again.

A United Nations convention on the rights of older persons that applies to older persons everywhere would provide a clear baseline, enshrined in law, to guide better policies, laws and services in future. It would put solidarity and respect for everyone's dignity to the fore as common values that we need to uphold at all times. It would challenge community attitudes, behaviours, norms and social constructions that keep us from living fairly and freely as equals when we are older. It would amplify the voices of older persons and help ensure that people, no matter what their age, can live their lives to the full.

This paper examines how the rights of older persons have been ignored and denied in many responses to the COVID-19 pandemic and how a convention that protects the rights of older persons everywhere would help build societies that are fair and just for all.

#### **EQUALITY & NON-DISCRIMINATION**

While international human rights law permits limitations on or derogations from rights in times of emergencies, these must not discriminate.¹ Despite this, age-based measures to restrict older persons' movement have been a common response to every stage of the COVID-19 pandemic. They have been proposed or implemented in countries around the world in the initial stages of lockdown and as countries come out of it. They include preventing people over a certain age, e.g. 65- or 70-years old to leave their homes,² go back to work,³ go to shopping malls⁴ and restaurants,⁵ participate in religious activities⁶ or use public transport.¹

While purportedly justified on the ground that older persons are more susceptible to severe impacts from contracting COVID-19, age-based measures do not take into account the diversity among older persons, and have not been based on or updated in light of the medical evidence. They also fail to consider the negative impact that long periods of isolation have on older persons' physical, mental and cognitive well-being.<sup>8</sup> They leave many older persons unable to access necessary medical or care and support services, their pensions, work, food, means of support, social protection or fundamentals of an adequate standard of living.<sup>10</sup>

As older people we like to move around and visit our friends to chat with them. But now, we are being told to minimize and stop our movements during this COVID-19 period. It's making us isolated and traumatised. I sell food and other items. The business wasn't bad. But now all the stores and shops in the town are closed. It has paralyzed my business! We were given two months food rations by the World Food Programme but the food we received is about to get finished within the first month. I do not know what is

going to happe<mark>n.</mark>

Martha Daniel Lul, 52, Internally Displaced Persons (IDPs) Camp at UN-House-POC 1, South Sudan<sup>11</sup>

Singling out one cohort of the population can also have a significant stigmatising and vilifying effect. Ageism has been exposed throughout the pandemic. This includes hate speech, where the pandemic has been called an opportunity to remove or cull older people, with some voices literally welcoming the virus as a "remover" of older persons. The rhetoric of influential decision-makers has been ageist, and we have seen the willful pitting of generation against generation in claims that responses to the pandemic are harming the young in order to save the old, and that older persons should be taxed to pay for sacrifices younger generations have made. Elsewhere the lives and deaths of older persons have not been afforded the same value as

younger people,<sup>17</sup> and older persons have been stigmatized, verbally abused and physically assaulted.<sup>18</sup>

We do not accept stigmatized remarks which can subtly make the idea that older persons, just for reason of their age, are not welcome in the public space and may represent an additional risk for spreading the pandemic.

Associação de Aposentados, Pensionistas e Reformados Open Letter to the Government of Portugal, 30 April 2020<sup>19</sup>

Separating generations may worsen intergenerational-tensions and ageist attitudes.<sup>20</sup> Age-based measures deny older people the opportunity to come out of retirement where their skills are needed during the pandemic, for example as health professionals,<sup>21</sup> and prevent them from playing their critical part, in solidarity with younger generations, to 'build back better', for example, through returning to work, volunteering or participating in community activities. In addition, as messages concerning heightened 'vulnerability' in older age groups are internalized, they may influence older persons' perception of their own ageing process and self-esteem, and decrease longevity, cognitive, physical and mental health.<sup>22</sup>

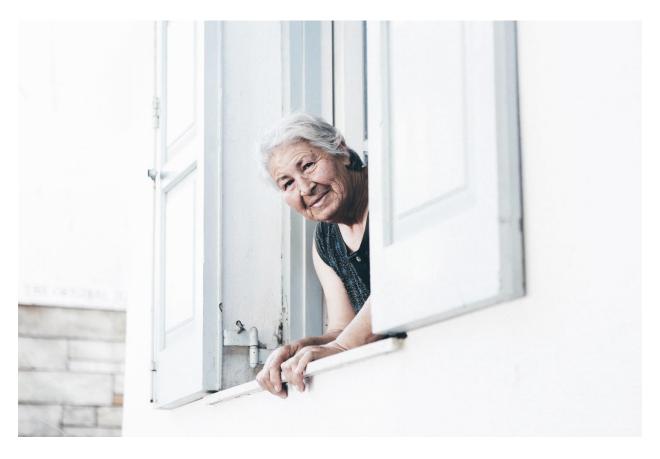


Photo by Nick Karvounis on Unsplash

A convention would recognize that we should all be treated equally regardless of age. It would result in internationally and nationally binding equality and non-discrimination laws that take age discrimination seriously.

The pandemic has shown that age discrimination is rarely treated with the same gravity in law and practice as other forms of discrimination. A convention would change this. Ageism would be recognised and treated as grave a violation of human rights as racism, sexism or ableism. Agebased measures in any future pandemic would face the same scrutiny as measures based on other prohibited grounds for discrimination such as gender, disability and race.

A convention would trigger legal reform to prohibit all forms of discrimination on the basis of older age across every aspect of life including measures to implement and enforce this prohibition. This includes the intersectional discrimination people experience based on a combination of factors such as age, sex or disability, and the cumulative discrimination that builds up over a period of time.

Governments would assess the impact of their policies and decisions, especially age-based measures on older persons, and would have to take deliberate steps to ensure older persons enjoy equality in reality. For example, older persons are more likely to be excluded from advances in information and communication technology. To avoid the disproportionate impact of physical distancing on older persons with limited access to digital technologies, governments would have to make extra efforts, such as recruit volunteers, employ alternatives to digital means, such as phone or letters, provide training and reduce the cost of internet access.

A convention would also encourage states to adopt policies and programmes to eliminate ageism, leading to more cohesive communities and societies with stronger intergenerational relationships. Finally, it would provide for older persons themselves to be involved in policy development and the power to access effective and enforceable remedies when they experience age discrimination.

Photo by Big Dodzy on Unsplash



#### **AUTONOMY**

Age-based measures also disproportionately restrict older persons' autonomy, liberty and freedom of choice compared with the rest of the population. Older persons have been prevented from exercising their autonomy in assessing the risks they face and their own free agency about how they manage and minimise those risks. The abilities and health status of older persons are very diverse; some older persons are more at risk, whereas others have been working as frontline workers in the pandemic or caring for others.

Older persons' right to make their own decisions has also been denied in cases where 'Do Not Resuscitate' orders have been placed on their care plans without their consent or where undue influence and pressure has been put upon them to sign such directives.<sup>23</sup> This not only denies their right to autonomy but also violates their rights to life and health.

Being old does not mean the end of our ability to be responsible citizens for the present and the future of our society.

Marie-Françoise Fuchs, founder of OLD'UP, France<sup>24</sup>

The use of upper age limits to exclude people from access to scarce medical resources, such as ventilators in COVID-19 triage protocols<sup>25</sup> has also denied older persons their right to give their own free and informed consent to their healthcare. This age-based rationing to deny older persons' access to scarce medical resources is not a new practice but has been brought to the fore in the pandemic. The use of age to determine the value of life is unethical, discriminatory and denies older persons their rights to exercise their autonomy, equitable access to health care and to life.<sup>26</sup>

A convention would recognize that our autonomy is no less important when we are older. It would offer concrete ways to recognise and support older persons' decision-making and would result in a greater respect for autonomy. Respect would be paid to older persons' wishes, values, will and preferences around every aspect of their lives, including their medical treatment.

By recognising the autonomy and independence of older persons, a convention would contribute to a necessary paradigm shift away from the current ageist and paternalistic assumption that older persons cannot make their own decisions and that others should decide what is in their 'best interest' to a legally binding presumption that recognises, supports and respects their right to do so in every aspect of their lives. It would trigger a range of support services around decision-making and safeguards to ensure the decisions, views and values, will and preferences of older persons are respected. Finally, it would mandate that older persons are included, and their voices heard and taken into account in policy and decision-making processes.

# CARE, SUPPORT & INDEPENDENT LIVING

The COVID-19 pandemic has exposed the lack of protection of older persons' rights in relation to care and support services. Lockdown measures, including the suspension of care and support services, have meant older persons have been unable to get the care and support they need in their homes or the community.

Care and support services have not been given sufficient personal protective equipment (PPE) for use in the community and in care homes in order to protect the lives of residents and staff.<sup>27</sup> Older residents have not been offered COVID-19 testing<sup>28</sup> and guidance was issued to not transfer them to hospital when they present with symptoms.<sup>29</sup> There has been widespread failure to prevent deaths in care homes,<sup>30</sup> and frequent failures to count the deaths in care homes<sup>31</sup> or include them in official statistics. Elsewhere, emergency measures have been introduced that reduced older persons' access to care and support services,<sup>32</sup> and removed funding for important social services.<sup>33</sup>

It's difficult for me to move around the house and I almost never go out. At first glance, when the pandemic began, it seemed that nothing had changed in my life. But now I live in constant fear and stress for my life, and the life of my loved ones. The volunteer's support is very necessary for me.

Klavdiya Kazakova, 79, Ukraine<sup>34</sup>



Photo by Siarhei Plashchynski on Unsplash

A convention would recognize that care and support are fundamental rights that we all may need at different times of our lives. It would result in care and support systems that actively promote independence and enable us to live independently in the community when we are older. Systems of care and support would be in place that can be expanded or adapted to future pandemic or other emergency contexts.

A convention that recognized the right to care and support in all settings in which older persons live would elevate the importance of care and support services and ensure that they are treated with the same seriousness as other services, such as healthcare. Better monitoring and rights-based regulation would be developed and implemented and additional resources would be allocated for their delivery. More and better-quality care and support services provided in home and community settings, including for example training and better working conditions for caregivers, would support older persons' right to choose where and with whom they live. Older persons would lead more independent lives, participating in their communities without exposure to the heightened risks associated with institutionalisation.

## FREEDOM FROM VIOLENCE, ABUSE & NEGLECT

Lockdown measures have put older persons at increased risk of violence, abuse and neglect. It has also exposed and exacerbated ageism, a risk factor for violence against older persons.<sup>35</sup> Older women are at particular risk where ageism intersects with gender inequalities. There has been an increase in violence, abuse and neglect in the community<sup>36</sup> and an increase in calls by older persons to violence and abuse helplines<sup>37</sup> and the police.<sup>38</sup> Older persons have also been subjected to abuse and neglect in care homes. Poor standards have been exposed<sup>39</sup> and restrictive visitor policies have increased the isolation of residents<sup>40</sup> increasing the risk of neglect. In some cases, older residents have been abandoned and left to die.<sup>41</sup>

During quarantine, my son and daughter-in-law began to neglect my needs. Previously, I did not notice their behaviour, but since all family members must stay home, I started feeling their bad attitude to me. They don't give me food and medicine on time and even don't talk to me. Sometimes my daughter-in-law yells at me. I feel like a burden to my family.

Older woman, 62, Osh province, Kyrgyzstan<sup>42</sup>



Photo by Samir Bol for Helpage International

A convention would recognize that violence, abuse and neglect of older persons is a human rights violation. It would generate specialist prevention and support systems around forms of violence, abuse and neglect experienced by older women and men. The heightened risk of violence, abuse and neglect of older persons would be recognised and anticipated in any future pandemic.

Recognising older persons' right to be free from violence, abuse and neglect in a new convention would result in greater awareness of the violence, abuse and neglect of older persons that takes place in public as well as private settings. Services would be put in place to monitor, prevent, respond to and remediate this violence, with legislation and policies adopted to ensure all forms are identified, investigated, prosecuted and punished. More financial resources would be allocated to implement these policies and older persons themselves would have access to necessary information and support.

#### HEALTH

Older persons' right to health has been denied in a number of ways during the pandemic. Some older persons have not been able to access the treatment they need for COVID-19.<sup>43</sup> Others have had no access to testing for the virus.<sup>44</sup> In some cases, older persons presenting with COVID-19 like symptoms have been turned away from health centres without being treated.<sup>45</sup>

Older residents in care homes have not been admitted to hospital. Some have been denied their right to give informed consent to their medical treatment with Do Not Resuscitate (DNR) orders being placed on the care plans of residents of care homes without their consent or as the result of undue influence.<sup>46</sup> Others have not had access to health or other information.<sup>47</sup> Upper age limits have been included to exclude older persons from access to scarce medical resources in COVID-19 triage protocols<sup>48</sup> and from participation in clinical trials.<sup>49</sup>

I cannot ignore the fact that I recently had an open-heart surgery and I do have chronic diseases, so I am highly concerned about my health. What if I acquire the virus and there is no capacity to treat me at the hospital? What if I don't survive COVID-19? Adding to that, in high-income countries they are prioritising the hospitalisation of younger generations. What will happen here when the situation worsens?

Nidaa Barakat, 54, Lebanon<sup>50</sup>

Access to non-COVID-19 related health services has been deprioritized or denied and some older people have been discharged early.<sup>51</sup> Elsewhere upper age limits deny older persons access to health insurance.<sup>52</sup>

Long periods of isolation have had negative and often devastating impacts on people with underlying health conditions, many of whom are older, including those needing palliative and end of life care, and on their families.<sup>53</sup>

A convention would recognize that we all have an equal right to the highest attainable standard of health whatever our age. It would result in health services that respond to older persons' health needs and do not discriminate against them. In future pandemics older persons would not be denied access to health care on the basis of their age or where they live.

Unpacking what the right to health means in the context of older age in a new convention would result in greater attention to aspects of the right such as non-discriminatory access to health services, access to palliative care, hospice and end-of-life care, availability and accessibility of health services, including specialised geriatric units, health literacy and health information in healthcare service delivery. There would be greater integration of health and social care services. Training in geriatrics and dementia and palliative care would be included in courses for all health care workers. Support with giving free and informed consent would be provided to those who need it, as well as services such as advanced decision-making so that older persons' wishes about their healthcare can be respected. Older persons could not be denied participation in clinical trials on the basis of their age so the understanding of the impact of new drugs for their conditions would not be limited to younger ages.

### **SOCIAL PROTECTION & SOCIAL SECURITY**

Disruptions to social security and social protection have left many older persons without access to the income, food and other forms of support they need to survive. This includes interruptions to, or suspensions of pension payments<sup>54</sup> and older persons being unable to access their pensions as banks have been closed or because they do not have ATM cards.<sup>55</sup> In other cases, older people have not had access to cash transfers, 56 food 57 or unemployment benefits.58



We might die of hunger before coronavirus, so how are we meant to stay alive?"

Zafor Alam, 62, Cox's Bazar, Bangladesh<sup>59</sup>

Elsewhere inadequate social security systems have put older persons at risk<sup>60</sup> and while many countries have expanded their social protection systems to mitigate the impact of lockdown measures,61 only a small proportion have adapted or expanded old age social protection measures. 62 Another concern is a lack of focus on equitable access to large cash transfer programmes where older persons are unaware of the scheme, have no access to the technology to register, are excluded by eligibility criteria or cannot access the cash distribution points.<sup>63</sup>



Photo by Johann Walter Bantz on Unsplash

A convention would recognize our right to social protection in old age. It would result in comprehensive social protection systems for older persons that ensure them an adequate standard of living. These systems would be guaranteed and expanded or adapted in times of crisis.

By clarifying what the rights to social protection and social security in older age mean, greater attention would be paid to not only ensuring that every older person has access to social protection and social security but also that those measures are of a high enough value, quantity and quality to ensure an adequate standard of living, adequate income security, access to health care, medication and assistive devices, and access to support and care services for autonomous and independent living. Schemes would be scrutinised to ensure they don't discriminate on any grounds, for example sex, disability, refugee, asylum or migrant status. Complaints and accountability mechanisms would be set up and older persons themselves would be able to participate in the design, management and administration of schemes and measures targeted at them.



#### **CONCLUSION**

We won't know the full impact of the response to the COVID-19 pandemic for some time. As well as the rights explored above, it is affecting our rights to work, to access to justice, to participate in society, and others. If we want to live in a world that is fair and just, a world where we don't lose our humanity as we get older, we must act now. A UN convention on the rights of older persons would help us build a solid foundation from which effective national laws and behaviour can emerge. It would provide specific answers that governments, the private sector and others need to make the right decisions about how to deliver services that respect our dignity in older age and build societies that are fair and just. And it would recognise that we all have the right to a future where we can age with dignity and participate equally. The time is now.

<sup>1</sup> See among others Article 4, ICCPR: Article 2(1), ICCPR and Art 2(2) ICESCR

- <sup>2</sup> See for example, <u>Colombia</u>, <u>Azerbaijan</u>, <u>Ireland</u>, <u>Sweden</u>, <u>Serbia</u>, <u>Philippines</u>, <u>France</u>, <u>Argentina</u>, <u>Tunisia</u>, Russia. Finland
- <sup>3</sup> See for example <u>Israel</u>
- <sup>4</sup> See for example <u>Dubai</u>
- <sup>5</sup> See for example <u>Dubai</u>, <u>Abu Dhabi and Ras Al Khaimah</u>
- <sup>6</sup> See for example Pakistan
- <sup>7</sup> See for example the **Philippines**
- <sup>8</sup> British Society of Gerontology Statement on COVID-19, 20 March 2020, point 6;
- https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2020-coronavirus-pandemic-eu-bulletin-june\_en.pdf
- <sup>9</sup> Pfeffer Baum B, North CS. Mental health and the Covid-19 pandemic. New England Journal of Medicine. 2020.
- <sup>10</sup> UN Policy Brief, <u>The impact of COVID-19 on older persons</u>, **1** May 2020, page 3; See also <a href="https://www.ageuk.org.uk/latest-press/articles/2020/05/sounding-the-alarm-about-the-rising-risk-of-malnutrition-among-older-people-during-lock-down/">https://www.ageuk.org.uk/latest-press/articles/2020/05/sounding-the-alarm-about-the-rising-risk-of-malnutrition-among-older-people-during-lock-down/</a>
- 11 https://www.helpage.org/newsroom/covid19-older-peoples-stories/martha-daniel-lul-/
- <sup>12</sup> Stigma is the disapproval or disgrace society attaches to a particular characteristic or illness. To stigmatise someone or a group of people is to apply that disapproval to them.
- <sup>13</sup> https://www.newsweek.com/boomer-remover-meme-trends-virus-coronavirus-social-media-covid-19-baby-boomers-1492190
- <sup>14</sup> https://twitter.com/greatermcr/status/1238501622919114753?s=20
- <sup>15</sup> https://www.hrw.org/news/2020/05/05/why-brazils-president-needs-change-his-tune-about-older-people
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- <sup>18</sup> https://www.theguardian.com/uk-news/2020/mar/23/three-teenagers-held-for-allegedly-coughing-at-elderly-couple-hertfordshire?CMP=share\_btn\_link
- <sup>19</sup> https://www.age-platform.eu/sites/default/files/Human\_rights\_concerns\_on\_implications\_of\_COVID-19 to older persons updated 18May2020.pdf
- <sup>20</sup> Ayalon et.al, <u>Aging in Times of the COVID-19 Pandemic: Avoiding Ageism and Fostering Intergenerational Solidarity</u>, 16 April 2020
- <sup>21</sup> https://www.age-platform.eu/sites/default/files/Human\_rights\_concerns\_on\_implications\_of\_COVID-19 to older persons\_updated\_18May2020.pdf
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- <sup>24</sup> https://www.oldup.fr/
- <sup>25</sup> See for example Maryland (USA), NICE (UK), SIAARTI (Italy)
- <sup>26</sup> UN Independent Expert on the human rights of older persons, "Unacceptable" UN expert urges better protection of older persons facing the highest risk of the COVID-19 pandemic', 27 March 2020, <a href="https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25748&LangID=E">https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25748&LangID=E</a>
- <sup>27</sup> https://www.rcn.org.uk/news-and-events/news/uk-rcn-demands-personal-protective-equipment-ppe-community-nurses-covid-19-010420
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- <sup>29</sup> https://www.dailymail.co.uk/news/article-8226675/Care-home-residents-asked-sign-letters-agreeing-WONT-hospital-COVID-19.html
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- $^{32} \ \underline{\text{https://www.theguardian.com/society/2020/mar/23/uks-emergency-coronavirus-bill-will-put-vulnerable-at-risk}$
- <sup>33</sup> https://www.euronews.com/2020/04/21/coronavirus-lockdown-in-moscow-elderly-struggling-to-cope-with-covid-19-restrictions
- 34 https://www.helpage.org/newsroom/covid19-older-peoples-stories/klavdiya-kazakova-ukraine/

<sup>35</sup> WHO, COVID-19 and violence against older people, 14 June 2020,

https://www.who.int/publications/m/item/covid-19-and-violence-against-older-people

- 36 https://bc.ctvnews.ca/tenfold-increase-in-elder-abuse-during-covid-19-pandemic-advocates-say-1.4896176
- <sup>37</sup> See for example <a href="https://www.abc.net.au/news/2020-04-29/coronavirus-queensland-elder-">https://www.abc.net.au/news/2020-04-29/coronavirus-queensland-elder-</a>

abuse/12188668; https://news.trust.org/item/20200511102348-9pf06;

https://www.abc.net.au/news/2020-04-29/coronavirus-queensland-elder-abuse/12188668;

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- <sup>48</sup> See for example Maryland (USA), NICE (UK), SIAARTI (Italy)
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- <sup>51</sup> https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2020-coronavirus-pandemic-eu-bulletin-june\_en.pdf and https://www.age-

platform.eu/sites/default/files/Human\_rights\_concerns\_on\_implications\_of\_COVID-

19 to older persons updated 18May2020.pdf

- 52 See for example <u>Ukraine</u>
- <sup>53</sup> Rodin et al, <u>The Suffering of Isolated Patients and Families The psychological and social implications of physical isolation for patients and families during the coronavirus pandemic</u>
- <sup>54</sup> https://www.helpage.org/newsroom/life-stories/emergencies/lola-grandma-rosita-76-malabon-city-the-philippines/
- <sup>55</sup> https://www.euronews.com/2020/04/21/coronavirus-lockdown-in-moscow-elderly-struggling-to-cope-with-covid-19-restrictions
- $^{56}$  https://punchng.com/were-old-poor-athe nd-hungry-yet-weve-received-no-cash-from-fg-lagos-vulnerable-persons/
- $^{57}$   $\underline{\text{https://www.ageuk.org.uk/latest-press/articles/2020/05/sounding-the-alarm-about-the-rising-risk-of-malnutrition-among-older-people-during-lock-down/}$
- <sup>58</sup> https://www.haaretz.com/opinion/editorial/treasury-shamelessly-refuses-to-help-israel-s-poorest-people-hit-by-covid-19-1.8838861 and
- https://www.citizensinformation.ie/en/social\_welfare\_social\_welfare\_payments/unemployed\_people/covid19\_pandemic\_unemployment\_payment.html
- <sup>59</sup> https://news.trust.org/item/20200511102348-9pf06
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- <sup>61</sup> https://www.socialprotection.org/discover/publications/responding-covid-19-improved-social-protection-older-people-8th-may-2020
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- <sup>63</sup> https://www.socialprotection.org/discover/publications/review-inclusion-older-people-ehsaas-emergency-cash-programme