Mandates of the Special Rapporteur on the rights of persons with disabilities; the Special Rapporteur on extrajudicial, summary or arbitrary executions; the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context; and the Independent Expert on the enjoyment of all human rights by older persons

REFERENCE:
AL GBR 5/2020

9 June 2020

Excellency,

We have the honour to address you in our capacity as Special Rapporteur on the rights of persons with disabilities; Special Rapporteur on extrajudicial, summary or arbitrary executions; Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context; and Independent Expert on the enjoyment of all human rights by older persons, pursuant to Human Rights Council resolutions 35/6, 35/15, 42/16, 34/9 and 42/12.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received **concerning the high number of deaths of persons with disabilities and older persons in adult care homes and other residential institutions, who have tested positive for COVID-19 in the United Kingdom of Great Britain and Northern Ireland.**

According to the information received:

Since the outbreak of COVID-19 in the United Kingdom of Great Britain and Northern Ireland, the Government has been recording and publishing daily data on the number of infections and deaths resulting from the virus. As of 4 June 2020, there had been 281,661 lab-confirmed COVID-19 cases in the UK and 39,904 deaths which occurred in hospital and other settings. The bulk of the deaths occurred in England (89.2%), followed by Scotland (6.0%), Wales (3,5%), and Northern Ireland (1.3%).[1] However, it is reported that real numbers could be much higher.

The COVID-19 pandemic has spread to the majority of UK's institutions and care homes for persons with disabilities and older persons, resulting in significant high numbers of deaths. The recording of data, including on residential care homes, is

[1] https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public and https://coronavirus.data.gov.uk/.

decentralised for England, Wales, Northern Ireland and Scotland, with information being published on various government websites, with differences in coverage and timeliness depending on the sources of data.

The Office for National Statistics (ONS) publishes weekly death data for England and Wales where COVID-19 was mentioned on the death certificate, as well as specific data for COVID-19 deaths of residents of care homes. As of 15 May 2020, ONS reported 14,573 deaths of residents of care homes, of which 65.1% occurred in hospitals, 28.3% in care homes, 4.6% in private homes and 1.3% in hospices.[2] This would be 35% of all COVID-19 deaths of care homes residents registered by ONS up to the 15 May 2020 (41,105 people[3]).

England

The Care Quality Commission (CQC) – the independent regulator of health and social care in England – specifically records COVID-19 related deaths that occur in adult care homes for persons with disabilities and older persons, as well as in mental health settings, based on statutory notifications by these institutions. While it is a legal requirement for service providers to immediately report deaths in care homes to the CQC, the latter only started publishing such data as of 10 April, four weeks after the beginning of the lockdown. Between 10 April and 15 May 2020, the number of deaths of persons with intellectual disabilities and/or autistic persons reported by service providers to CQC was 386, as compared to 165 in the same period in 2019. This constitutes a 134% increase in the number of death notifications this year. Of these 386 deaths, 206 were as a result of suspected and/or confirmed COVID-19, and 180 were unrelated to it.[4]

The CQC has been accused of failing to alert the relevant authorities to the mounting death toll caused by COVID-19 in adult care homes early on; to openly represent the voice and needs of the sector for PPE, testing and tracing, and other needed resources; and to stop routine visits to care homes early on, thus failing to protect residents.[5]

With regards to persons with psychosocial disabilities, CQC separately records deaths of persons involuntarily detained or subject to the Mental Health Act of 1983. During the period from 1 March to 1 May 2020, mental health providers notified the CQC of the death of 106 people subject to this Act, 54 of whom are

[2]https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/latest and https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredweeklyinenglandandwalesprovisional/weekending15may2020.

[3]https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredinenglandandwales.

[4] https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability.

[5] https://www.relres.org/letter-cqc/.

confirmed or suspected cases of COVID-19. On 7 and 11 May 2020, the CQC expressed public concern on the doubling of death notifications due to COVID-19 in mental health settings, which mirrors a rise in notifications from other sectors, including adult care homes. CQC called upon the relevant services to ensure they take all measures necessary to manage cases of COVID-19 in their services, including having enough supplies of PPE and adequate training and staffing.[6]

Furthermore, the National Health Service (NHS) published daily and weekly data on COVID-19 deaths of persons with intellectual disabilities notified to the Learning Disabilities Mortality Review (LeDeR) programme. Between 16 March and 29 May 2020, LeDeR reported 1,285 deaths of persons with intellectual disabilities due to various causes, out of which 565 were confirmed and unconfirmed COVID-19 deaths occurred in hospitals and other settings. As notification to the LeDeR programme is not mandatory, it is unlikely that all deaths of persons with intellectual disabilities are counted.[7]

According to a study on "Estimates of mortality of care home residents linked to the COVID-19 pandemic in England*"* dated 17 May 2020, the share of all probable COVID-19 deaths *in* care homes is 27%, and the share of all probable deaths *of* care home residents is 38%. Data on registered COVID-19 deaths among care home residents only accounts for an estimated 54% of all excess deaths in care homes, compared to the same period in 2019.[8]

Wales

The Care Inspectorate Wales (CIW) published data regarding deaths occurred in adult care homes in Wales based on notifications by these institutions. Between 1 March and 29 May 2020, CIW has been notified of 2,669 deaths of adult care home residents, out of which 668 were suspected or confirmed COVID-19 related deaths. The overall number of deaths is 94% higher than deaths reported for the same time period in 2019, and 58% higher than for the same period in 2018.[9]

Scotland

According to the National Records of Scotland, as of 31 May 2020, out of a total of 3,911 registered deaths where COVID-19 was mentioned on the death

[6] https://www.cqc.org.uk/news/stories/our-concerns-about-mental-health-learning-disability-autism-services and https://www.cqc.org.uk/news/stories/our-concerns-about-mental-health-learning-disability-autism-services.

[7] https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/.

[8] https://ltccovid.org/wp-content/uploads/2020/05/England-mortality-among-care-home-residents-report-17-May.pdf.

[9] https://gov.wales/notifications-deaths-residents-related-covid-19-adult-care-homes-1-march-22-may-2020-html.

certificate, 91% (i.e., 3,546 deaths) were residents of adult care homes.[10] Of all deaths of care home residents involving COVID-19, 46% died in adult care homes, 47% in hospital and 7% at home or in non-institutional settings.[11]

Since 11 April 2020, the Care Inspectorate of Scotland, the regulatory body charged with ensuring that care standards are met in Scotland, collects data on adult care homes with reported suspected COVID-19. As of 5 June 2020, a total of 6,170 suspected COVID-19 cases had been recorded in 675 adult care homes, comprising of 62% of all adult care homes in Scotland.[12]

Northern Ireland
The Department of Health of Northern Ireland publishes daily data on COVID-19 related deaths, which stood at 536 on 5 June 2020. The number of deaths of care homes residents is not available. However, out of a total of 4,776 individuals with a positive lab test for COVID-19, 170 were confirmed or suspected COVID-19 cases in adult care homes.[13]

While we do not wish to prejudge the accuracy of the information received, serious concern is expressed about the above-mentioned alleged violations, in particular as they pertain the right to life, the right to health and to life-saving interventions, amid the pandemic, of persons with disabilities and older persons in residential care institutions in the UK. We are also concerned that, unless prompt measures are taken, more COVID-19 related deaths will continue to be registered in these settings.

We are extremely concerned that these allegations appear to be violating the right of persons with disabilities and older persons to life, protected by article 3 of the Universal Declaration of Human Rights, article 6(1) of the International Covenant on Civil and Political Rights (ICCPR), ratified by the United Kingdom on 20 May 1976; and by article 10 of the Convention on the Rights of Persons with Disabilities (CRPD), ratified on 8 June 2009. Under the CRPD, States must protect the inherent right to life of persons with disabilities and take all necessary measures to ensure its effective enjoyment, including by ending preventable deaths. Furthermore, article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), ratified by the United Kingdom on 20 May 1976, and article 25 of the CRPD, guarantees the right to physical and mental health. In this regard, States have an obligation to guarantee a number of lifesaving health-related services.

[10] This number differs from the count of deaths published daily on the gov.scot website, because the latter is based on deaths of those who have tested positive for COVID-19.
[11] https://www.nrscotland.gov.uk/covid19stats.
[12] https://www.gov.scot/publications/coronavirus-covid-19-trends-in-daily-data/.
[13]https://app.powerbi.com/view?r=eyJrIjoiZGYxNjYzNmUtOTlmZS00ODAxLWE1YTEtMjA0NjZhMzlmN2JmIiwidCI6IjljOWEzMGRlLWQ4ZDctNGFhNC05NjAwLTRiZTc2MjVmZjZjNSIsImMiOjh9.

We wish to further stress that worldwide, institutional settings have become COVID-19 hotspots, highlighting systemic challenges in these settings. Persons with disabilities in institutional settings and older persons in care homes are experiencing the highest rates of infection and mortality from COVID-19. Furthermore, persons deprived of their liberty, especially those in vulnerable or high-risk situation such as persons with psychosocial disabilities under the Mental Health Act, are likely to be more vulnerable to COVID-19 outbreak than the general population because of the confined conditions in which they live together for prolonged periods of time.

Article 14 of the CRPD on liberty and security of person prohibits unlawful and/or arbitrary detention on grounds of disability, including in mental health facilities. Moreover, in response to the pandemic, the World Health Organization has recommended reducing the number of people in psychiatric hospitals, wherever possible, by implementing schemes of early discharge, together with provision of adequate support for living in the community.[14]

We also express grave concern about the placement of person with disabilities in segregated institutions, which cannot be considered homes. Such facilities, both large and small, fail to meet international standards on the rights of persons with disabilities, including the right to full and effective participation and inclusion in society, respect for individual choice and control over decisions affecting their lives, as well as non-segregation from the community.

In connection with the above alleged facts and concerns, please refer to the **Annex on Reference to international human rights law** attached to this letter which cites international human rights instruments and standards relevant to these allegations.

As it is our responsibility, under the mandates provided to us by the Human Rights Council, to seek to clarify all cases brought to our attention, we would be grateful for your observations on the following matters:

1. Please provide any additional information and comments you may have on the above-mentioned concerns.

2. Please provide information on the measures taken to guarantee persons with disabilities and older persons their right to life and to access to life-saving health interventions on an equal basis with others, and to prevent further deaths.

3. Please provide information on measures taken to: a) prevent the exposure to COVID-19 of persons with disabilities and older persons in residential institutions; b) prepare and manage COVID-19 infections in institutions;

[14] https://www.who.int/publications-detail/disability-considerations-during-the-covid-19-outbreak

c) reduce the number of deaths *in* residential institutions and *of* institutions' residents.

4. Please provide information on any plans to move towards a deinstitutionalization process in close coordination with persons with disabilities, aimed at reducing the number of persons with disabilities in institutions and replacing such institutions with community-based services that support their right to live independently and to be included in the community.

We would appreciate receiving a response within 60 days. Passed this delay, this communication and any response received from your Excellency's Government will be made public via the communications reporting website. They will also subsequently be made available in the usual report to be presented to the Human Rights Council.

While awaiting a reply, we urge that all necessary interim measures be taken to halt the alleged violations and prevent their re-occurrence and in the event that the investigations support or suggest the allegations to be correct, to ensure the accountability of any person(s) responsible for the alleged violations.

Please accept, Excellency, the assurances of our highest consideration.

Catalina Devandas-Aguilar
Special Rapporteur on the rights of persons with disabilities

Agnes Callamard
Special Rapporteur on extrajudicial, summary or arbitrary executions

Dainius Puras
Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

Balakrishnan Rajagopal
Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context

Claudia Mahler
Independent Expert on the enjoyment of all human rights by older persons

Annex
Reference to international human rights law

In connection with above-alleged facts and concerns, and without prejudge to the accuracy of these allegations, we would like to draw the attention of your Excellency's Government to the relevant international norms and standards.

The right to life of persons with disabilities and older persons is protected by article 3 of the Universal Declaration of Human Rights, article 6(1) of the International Covenant on Civil and Political Rights (ICCPR), ratified by the United Kingdom on 20 May 1976; and by article 10 of the Convention on the Rights of Persons with Disabilities (CRPD), ratified on 8 June 2009. Under the CRPD, States must protect the inherent right to life of persons with disabilities and take all necessary measures to ensure its effective enjoyment, including by ending preventable deaths.

The Human Rights Committee has noted that the "right to life has been too often narrowly interpreted. The expression "inherent right to life" cannot properly be understood in a restrictive manner, and the protection of this right requires that States adopt positive measures." Violations of the right to life can result not only from criminal intent but also from acts of omission or commission; in other words, from a situation where the State "knew or should have known" that such deaths would occur but, in the context of diverse and intersecting discriminations inhibiting exercise of economic, social and cultural rights, it failed to take action that could have prevented such deaths.

International human rights law places particular and explicit emphasis on the obligation of States to guarantee lifesaving procedures and health-related services.

In this connection, the right to physical and mental health is protected by article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), ratified by the United Kingdom on 20 May 1976, as well as by article 25 of the CRPD. The right to health includes access to timely, acceptable, and affordable health care of appropriate quality, on an equal basis with others. In this context, States should take steps to achieve the full realization of the right to health to prevent discriminatory denial of health care and ensure that persons with disabilities and older persons enjoy the highest attainable standard of health.

With regard to the realization of the right to health of older persons, the Committee on Economic, Social and Cultural Rights, in its general comment No. 14 (2000), reaffirmed the importance of an integrated approach, combining elements of preventive, curative and rehabilitative health treatment. In this regard, States must establish quality monitoring and effective and transparent accountability mechanisms for public and private care settings and that they provide remedies in case violations are

detected, for instance through a dedicated complaint mechanism (A/HRC/33/44, para. 44).

The institutionalization of persons with disabilities, including older persons with disabilities, stands in contravention with the right to live in dignity and autonomy, and further perpetuates the social exclusion and segregation of persons with disabilities. Article 19 of the CRPD guarantees the right of persons with disabilities to choose their place of residence, and where and with whom they live on an equal basis with others, without being obliged to live in a particular living arrangements, and requires State Parties to ensure "access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from the community". Such a segregated institutionalization of persons with disabilities, including older persons with disabilities, would also contravene the non-discrimination dimensions of the right to adequate housing, under the ICESCR. Furthermore, article 14 of the CRPD on liberty and security of person prohibits unlawful and/or arbitrary detention on grounds of disability, including in mental health facilities.