

Mandates of the Special Rapporteur on the rights of persons with disabilities; the Special Rapporteur on extrajudicial, summary or arbitrary executions; and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

REFERENCE:
AL GBR 10/2018

20 August 2018

Excellency,

We have the honour to address you in our capacities as Special Rapporteur on the rights of persons with disabilities; Special Rapporteur on extrajudicial, summary or arbitrary executions; and Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health pursuant to Human Rights Council resolutions 35/6, 35/15 and 33/9.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received concerning a range of alleged human rights violations perpetrated against persons with disabilities within public health facilities in the United Kingdom of Great Britain. These allegations, which occurred between 2007 to 2018, include inadequate treatment within healthcare services leading in numerous cases to the death of persons with intellectual disabilities amount to discrimination, and constitute violations of the right to health and the right to life.

According to the information received:

In 2007, a report called *Death by indifference* by Mencap, a United Kingdom organization for persons with learning disabilities, focused on the premature deaths of five men and one woman with intellectual disabilities in public healthcare facilities and alleged that these deaths were avoidable, and were the result of institutional discrimination, indifference, lack of training and a very poor understanding of the needs of persons with learning disabilities.¹ In several cases, persons with intellectual disabilities were considered to be unable to provide consent and therefore, discharged from receiving healthcare services or given treatment that they had not consented to.² The Health Services and Parliamentary Ombudsman for England investigated these deaths, and issued a report in 2009 called *Six lives: the provision of public services to people with learning disabilities*, which stated: "Our investigation reports illustrate some significant and distressing failures in service across both health and social care, leading to

¹ *Death by indifference: Following up on the Treat me right! report*, March 2007, page 4.
<https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf>

² *Id* at p. 6-7, 21.

situations in which people with learning disabilities experienced prolonged suffering and inappropriate care.”³

In 2008, Sir Jonathan Michael, a doctor at St. Thomas’ Hospital Medical School, led an independent inquiry into access to healthcare for persons with intellectual disabilities, and issued a *Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. It found that despite legislative safeguards, “people with learning disabilities have higher levels of unmet needs and receive less effective treatment, despite the fact that the Disability Discrimination Act and the Mental Capacity Act set out a clear legal framework for the delivery of equal treatment.” These reports resulted in the establishment of the Confidential Inquiry into the Premature Deaths of Learning Disabled People (CIPOLD) led by a team from the University of Bristol.

In March 2013, the CIPOLD Inquiry in its *Final Report* reviewed the deaths of 247 persons with intellectual disabilities that took place between 2010 and 2013 within five Primary Care Trusts in the South West of England. It found that 42% deaths investigated were premature and that women with intellectual disabilities died on average 20 years before the mainstream population and men died 13 years earlier.⁴ The CIPOLD report recommended that the government set up a National Learning Disability Mortality Review Body to investigate these deaths.⁵ As a result, the government commissioned the Bristol University team to do further work investigating the deaths of persons with intellectual disabilities with the establishment of the Learning Disabilities Mortality Review (LeDeR) in 2017.

On 4 July 2013, an 18 year old autistic man died in an assessment and treatment unit run by Southern Health National Health Service (NHS) Foundation Trust, because he was left unsupervised in a bathtub, despite also having epilepsy. A campaign to gain answers and accountability for his death led the NHS England to commission a review into the deaths of persons with intellectual disabilities from April 2011 to March 2015 in the care of NHS Foundation Trust.

In December 2015, the review found that less than 1% of the deaths in Learning Disability services were investigated while over 30% of deaths in Adult Mental Health services were investigated.⁶ The review indicated that there was no effective systematic management and oversight of the reporting of deaths and the

³ *Six lives: the provision of public services to people with learning disabilities*, 2009, p. 3. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250750/0203.pdf.

⁴ *Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD): Final Report*, 2013, p. 13, 24. <https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>.

⁵ *Id.* at pp. 121-122.

⁶ *Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015*, December 2015, p. 14, <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>.

investigations that followed.⁷ Additionally, despite having comprehensive data relating to the deaths, it was found by the review that the NHS Foundation Trust failed to effectively understand mortality and issues relating to the deaths of its learning disability service users.⁸ There is no information available regarding any measures taken as a result of this review.

In 2016, the Secretary of State for Health and Social Care commissioned an investigation by the Care Quality Commission (the health and social care regulator) into how NHS Trusts identify, investigate and learn from the death of its users. This investigation reported its findings in December 2016 and found that there were inconsistencies across services in reporting, timeliness of investigations, and confusion regarding standards and guidance in involving families throughout the process after a relative had died.⁹ The families and those providing support to persons with learning disabilities who had died often had poor experiences of investigations and were not told what their rights were or how to access support.¹⁰ They also found “that the level of acceptance and sense of inevitability when people with a learning disability or mental illness die early is too common.”¹¹ There is no information available regarding any measures taken as a result of this investigation.

On 4 May 2018, LeDeR published its first *Annual Report* which included 103 reviews out of 1311 reported deaths requiring investigation from 1 July 2016 to 30 November 2017.¹² The report indicated that mortality rates have worsened over time for persons with learning disabilities. The life expectancy of women with learning disabilities is 56 and 59 for men, compared to general population median age at death of 85.3 years (women) and 81.8 years (men).¹³ In 13% of cases investigated, the individual’s health had been adversely affected by either delays in care or treatment, gaps in service provision, organizational dysfunction, or neglect or abuse by healthcare professionals.¹⁴

While we do not wish to prejudge the accuracy of the allegations made above, we express concern about the alleged human rights violations perpetrated against persons with intellectual disabilities in the United Kingdom within the NHS system. We call on the State to exercise due diligence to prevent, investigate, prosecute and provide remedies for the deaths of persons with intellectual disabilities who were discriminated on the basis of disability. We express concern at the allegations of inadequate access to healthcare and

⁷ *Id.* at p. 16.

⁸ *Ibid.*

⁹ *Learning, candour and accountability: A review of the way NHS trusts review and investigate the deaths of patients in England*, December 2016, pp. 6-7. <https://www.cqc.org.uk/sites/default/files/20161213-learning-candour-accountability-full-report.pdf>.

¹⁰ *Id.* at p. 6.

¹¹ *Id.* at p. 2.

¹² *Annual Report: December 2017*, 4 May 2018, p. 7.

<http://www.bristol.ac.uk/university/media/press/2018/leder-annual-report-final.pdf>.

¹³ *Id.* at pp. 6, 18.

¹⁴ *Id.* at p. 7.

discrimination. Therefore, we urge the State to ensure accountability and to provide redress for the families of victims and to institute changes into the NHS system to prevent such violations from occurring in the future.

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.

We appreciate your Excellency's Government response dated 16 March 2018 to a previous communication (see AL GBR 8/2017 of 18 January 2018) and take good note of the Equality Act 2010, which legally protects people from discrimination on various protected grounds, including race and disability. We also take note of the ongoing work of the Mental Welfare Commission for Scotland, which protects and promotes the human rights of persons with psychosocial disabilities, intellectual disabilities, dementia and related conditions.

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 therefore be grateful for your observations on the following matters:

1. Please provide any additional information and/or comment(s) you may have on the above-mentioned allegations.
2. Please provide the details, and where available the results, of any further investigations, including judicial or other inquiries, and prosecutions carried out in relation to the premature death of persons with intellectual disabilities within the National Health Service, including changes introduced in healthcare services as well as remedies and redress provided to the families of the victims.
3. Please provide the details on what measures have been taken to prevent, detect, report and address all forms of omission or abuse perpetrated against persons with intellectual disabilities in the National Health Service.
4. Please explain what measures have been taken to inform and raise awareness among persons with intellectual disabilities and their families on how to identify and facilitate their access to complaint and reporting mechanisms against inadequate access to healthcare or discrimination within the National Health Service.
5. Please provide information and details on any measures taken regarding accountability mechanisms to address the concerns identified in the various reports on the National Health Service.

6. Please provide information about any measures that will be taken to implement the recommendations contained in the LeDeR report of May 2018.
7. Please provide information on any measures taken to raise the awareness and provide training to personnel and caregivers within the National Health Service directly providing service to persons with intellectual disabilities.

We would appreciate receiving a response within 60 days. Your Excellency's Government's response will be made available in a report to be presented to the Human Rights Council for its consideration.

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

Annex

Reference to international human rights law

In connection with above alleged facts and concerns, we would like to draw your attention to a number of international human rights treaties ratified by the United Kingdom which are relevant in situations of negligence or abuse perpetrated against persons with disabilities in the context of public and private health institutions.

We would like to refer to the Convention on the Rights of Persons with Disabilities (CRPD), ratified by the United Kingdom on 8 June 2009, and particularly to articles 4 (general obligations), 5 (equality and non-discrimination), 8 (awareness-raising), 10 (right to life), 12 (equal recognition before the law), 13 (access to justice), 16 (freedom from violence and abuse), 17 (right to personal integrity) and 25 (health). We would also like to refer to the International Covenants on Civil and Political Rights (ICCPR) and on Economic, Social and Cultural Rights (ICESCR), both ratified by the United Kingdom on 24 May 1976.

We would like to remind your Excellency's Government that article 10 of the CRPD recognizes and protects the right to life of all persons with disabilities on an equal basis with others. The Committee on the Rights of Persons with Disabilities has expressed in several instances its concerns about the lack of preventative measures and disaggregated data on, inter alia, the causes and numbers of deaths of persons with disabilities in hospitals, psychiatric facilities, institutions, group homes or other facilities (see e.g. CRPD/C/MNE/CO/1 and CRPD/C/CYP/CO/1).

The ICCPR also recognizes under article 6 the inherent right to life of every human being. In general comment 6 of the Human Rights Committee, this right has been interpreted to include the State adopting positive measures to see the effective realization of this right (para. 5). In this regard, States not only have to refrain from intentional and/or unlawful deprivation of life, but must also take appropriate measures to reduce mortality and safeguard the lives of those within their jurisdiction. Moreover, in connection to the right to access justice, States have an obligation to investigate all deaths occurring in circumstances where the substantive obligations to protect the right to life may have been breached.

Regarding the right to health, we would like to bring your attention to ICESCR article 12 which enshrines the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The general comment No. 14 of the Committee on Economic, Social and Cultural Rights stresses that violations of the right to health can also occur through the omission or failure of States to take necessary measures arising from legal obligations. The Committee has also highlighted the need to ensure that public and private providers of health services and facilities comply with the principle of non-discrimination in relation to persons with disabilities

Additionally, article 25 of the CRPD recognizes that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination. This includes all the elements of the right to health framework, including,

inter alia, freedoms, entitlements, participation, monitoring and accountability. Accordingly, States must *inter alia* provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons; and require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent.

We would like to stress that the right to enjoyment of the highest attainable standard of health is intertwined with other provisions of the CRPD, including article 5 on non-discrimination, article 12 on equal recognition before the law, article 13 on access to justice, article 16 on freedom from exploitation, abuse and violence, and article 17 on personal integrity.

Under article 5, States have an obligation to prohibit all forms of discrimination based on disability and to guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds. This includes the prohibition of discrimination in health care. Discrimination can occur on the basis of an actual or perceived impairment and can include the attitudinal barriers in providing services for persons with disabilities.

Article 12, in conjunction with article 25, upholds the right to health care on the basis of free and informed consent. State parties have an obligation to require all health and medical professionals to obtain the free and informed consent of persons with disabilities prior to any treatment. All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities (see CRPD/C/GC/1, para. 41). In cases where significant efforts have been made and it is not possible to obtain an individual's free and informed consent or to ascertain their will and preferences, including through the provision of support and accommodations, the standard of "best interpretation of the will and preference" should be applied as a last resort (see A/73/45390 and CRPD/C/GC/1, para. 21).

Article 16 of the CRPD recognizes the right to be free from violence and abuse and article 17 recognizes the right to personal integrity, including freedom from non-consensual medical treatment (see A/73/45390). In addition, States have an obligation under article 4(i) of the CRPD to promote the training of professionals and staff working with persons with disabilities so as to better provide the assistance and services guaranteed by the treaty. In conjunction with this right, article 8 of the same Convention requires States to promote the training of health professionals providing services to persons with disabilities.