

Mandates of the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

REFERENCE:
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Excellency,

We have the honour to address you in our capacity as Special Rapporteur on the rights of persons with disabilities 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 and 33/9.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received concerning allegations of violations related to the rights to life, discrimination, cruel and degrading treatment of Mr. Roger Philip Foley, as well as the denial of adequate healthcare and community support.

According to the information received:

Mr. Roger Philip Foley is a Canadian citizen born on 16 September 1975 in Ottawa. He has a progressing neurodegenerative condition known as Spinocerebellar Ataxia.

From December 2013 to February 2016, Mr. Foley received healthcare and personal support at his home in London, Ontario. The service was provided to him by a private agency, namely Cheshire Homes of London Ontario, contracted directly by the South-West Local Health Integration Network (SW LHIN).

It has been alleged that due to the poor quality of healthcare and the inadequate support provided by the agency, Mr. Foley's physical and mental integrity has rapidly deteriorated. For lack of other alternatives, in February 2016, Mr. Foley was transferred to the Victoria Hospital in London, Ontario. This was supposed to be a temporary arrangement until full-time, safe, and appropriate community based healthcare and support was arranged. However, as per the information received up to date Mr. Foley is still at Victoria Hospital, C building, 6th Floor, Medical Ward.

Mr. Foley has been trying without success to access healthcare and personal support in the community. On 17 March 2016, he applied for Self-Directed Funding, which is a province-wide program administered by the Centre for Independent Living in Toronto (CILT) and funded by the Ontario Ministry of

Health. This arrangement gives persons with disabilities the possibility of choosing a service provider and control over the services they want to receive. However, his initial application was rejected and he had to follow the appeal procedure.

On 29 March 2019, the South-West Local Health Integration Network (SW LHIN) finally confirmed his eligibility and offered to put him on a waiting list. However, following a re-structuring of Ontario's health system, the Local Health Integration Networks have been abolished, and currently there is uncertainty as to who will take responsibly for and ensure delivery of necessary home and community based healthcare and support that Mr. Foley requires.

It has been reported that during his stay at the Victoria Hospital, medical staff subjected Mr. Foley to verbal and physical abuse and, on many occasions, have deliberately ignored Mr. Foley's requests for assistance with his vital needs and support for the use of the Hoyer lift.

In April 2018, the medical staff reportedly denied him proper medical treatment, and withdrew food and water for 20 days, putting his life at serious risk. This led to life-threatening consequences, including life-threatening metabolic acidosis and gastroparesis.

According to the information received, throughout his stay at the hospital Mr. Foley faced pressure to return home and to accept the service provided by the same private agency whose reported inadequate care led to the worsening of his physical and mental integrity in the first place and forced him to seek placement at the hospital. He was reportedly told that his options were a forced discharge, a charge of a daily fee of CAD 1800.00 if he wished to continue his stay at the hospital, or assisted death. Furthermore, on four occasions some hospital staff reportedly attempted to coerce Mr. Foley to consider Medically Assisted Death. These attempts went as far as scheduling appointments for him with the doctor about the administration of medical assistance in dying.

We have also been informed that, in spite of lack of evidence, the Ontario Crown Attorney and the Police initiated an investigation against Mr. Foley. He was charged with assaulting a nurse who, according to Mr. Foley's accounts, presented false accusations of being bitten while attending him in April 2018. It is alleged that Mr. Foley's already precarious situation is further worsened by having to defend himself from hospital staff that failed to provide him with the essential healthcare and support.

According to the information received, it was only after heightened advocacy from his lawyer and family, that Mr. Foley was transferred to another unit at the

same hospital where he receives better healthcare and support. The new unit is better equipped for the administration of proper healthcare to persons with disabilities and gives them access to assistive equipment they need to eat, drink and take medicines. However, Mr. Foley continues to express his desire to leave the hospital and return home with the adequate provision of healthcare and support.

In addition, Mr. Foley has reportedly brought his concerns regarding the lack of safeguards for assisted dying and abuses faced by persons with disabilities to the attention of the Attorney General of Canada.

On 14 February 2018, Mr. Foley filed a case to challenge the Assisted Dying provisions as a victim of coercion into assisted dying without being offered any other choices or any support to continue his life with dignity. He has challenged the constitutionality of federal and the Ontario legislation and sought remedies under the Charter for Human Rights for violations related to his rights to life, liberty and security of the person, discrimination, and for cruel and degrading treatment. There are, however, no injunctive relief options for constitutional cases, and Mr. Foley's challenge will not afford him the remedies he needs. Mr. Foley has sought the intervention of the Ombudsman and the Ministry of Health of Ontario. However, he has not received a response from them.

Without prejudging the accuracy of these allegations, we wish to express serious concern about the situation of Mr. Foley, in particular about the reported threats to his right to life and denial of appropriate healthcare and support to live a dignified and independent life in the community.

In the context of the allegations raised in this communication, we are deeply concerned that instead of being offered access to community-based healthcare and support to live with dignity, Mr. Roger Philip Foley was suggested to request medically assisted dying. Moreover, we are concerned that the victim has been denied appropriate healthcare and access to the medical interventions to minimize and prevent life-threatening consequences. Furthermore, he has been waiting for more than three years now to get access to the range of in-home, and other community support services that would allow him to live in the community.

In connection with the above alleged facts and concerns, we would like to refer your Excellency's Government attention to the Convention on the Rights of Persons with Disabilities (CRPD), ratified by Canada on 11 March 2010. Under article 10 of the CRPD, Canada must protect the inherent right to life of persons with disabilities and take all necessary measures to ensure its effective enjoyment, including ending preventable deaths.

This obligation is complemented by article 3 of the Universal Declaration of Human Rights and article 6 (1) of the International Covenant on Civil and Political Rights (ICCPR), ratified by Canada on 19 May 1976. Concerning the medical assistance in dying, in their General Comment 36, the Human Rights Committee has noted that States parties that allow medical professionals to provide medical treatment or the medical means in order to facilitate the termination of life must ensure the existence of robust legal and institutional safeguards to verify that medical professionals are complying with the free, informed, explicit and, unambiguous decision of their patients, with a view to protecting patients from pressure and abuse. The protection of the right to life requires that States must provide legal protections and effective guarantees against all forms of discrimination. Any deprivation of life based on discrimination in law or fact is ipso facto arbitrary in nature. Persons with disabilities are also entitled to specific measures of protection so as to ensure their effective enjoyment of the right to life on equal basis with others, such as ensuring access of persons with disabilities to essential facilities and services. (CCPR/C/GC/36 paras. 9, 24 and 61).

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 Canada on 19 May 1976. In this connection, States should take all necessary steps to provide health services to achieve the full realization of the right to health. In the case *Toussaint v. Canada*, the Human Rights Committee concluded that Canada is obliged to adopt health-related positive measures when there are reasonably foreseeable threats and life-threatening situations that could result in loss of life, as part of its obligations under ICCPR article 6. At the minimum, Canada must provide access to existing healthcare services that are reasonably available and accessible when lack of access to healthcare would expose a person to a reasonably foreseeable risk that could result in loss of life. Denying this healthcare coverage was considered by the Committee as grounds for violations of the right to life (CCPR/C/123/D/2348/2014, paras 11.1, 11.5, & A/HRC/41/34/Add.2 para 23-25).

Specifically on the right to health of persons with disabilities, article 25 of the CRPD recognizes that health services should be provided as close as possible to people's own communities and requires States, inter alia, to prevent and eliminated discriminatory denial of healthcare or health services or food and fluids on the basis of disability.

The obligation to secure the right to health should be read in conjunction article 19 of the CRPD that secures 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 and are not obliged to live in a particular living arrangements” as well as provides for the State Parties’ obligation 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”.

Article 26 of the CRPD complements the obligation to guarantee health services needed by persons with disabilities with comprehensive habilitation and rehabilitation services and programmes, which are key to maintain a good health state and live independently. Access to essential habilitation and rehabilitation, to essential assistive devices and to essential health services needed by persons with disabilities owing to their impairment should be considered as core obligations that are subject to immediate realization (see A/73/161).

With regard to allegations that the victim has been subjected to physical and psychological pressure - such as denial of food and water, denial of healthcare , and threats to charge him large fees for his stay at the hospital and wrongful prosecution - to force him to discharge from the hospital, Article 15 (1) and (2) of the CRPD, prohibits torture or cruel, inhuman or degrading treatment or punishment and obliges States parties to take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

According to article 16 of the CRPD, States parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities from all forms of exploitation, violence and abuse.

The full texts of the human rights instruments and standards recalled above are available on www.ohchr.org or can be provided upon request.

In view of the urgency of the matter, we would appreciate a response on the initial steps taken by your Excellency's Government to safeguard the rights of the above-mentioned person(s) in compliance with international instruments.

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 information and any comment you may have on the above-mentioned allegations.
2. Please indicate what measures have been take to ensure Mr. Foley's access to healthcare to manage his medical condition and alleviate pain, to prevent the deterioration of his physical and mental integrity, and to avoid life-threatening consequences.

3. Please indicate what support services in the community were provided to Mr. Foley to prevent his institutionalization at the hospital, including existing legislation, policy and allocation of financial resources.
4. Please provide information about any investigation conducted into the allegations of physical and verbal abuse perpetrated against Mr. Roger Philip Foley, including withdrawal of food and water.
5. Please provide information about any investigation conducted into the allegations of pressure exerted to Mr. Foley to consider medically assisted dying before being provided with healthcare and support services to continue living with dignity in the community.
6. Please provide information regarding the measures taken to ensure that the medical assistance in dying is provided in a way that complies with international human rights obligations, including the conditions and safeguards to prevent abuse, monitoring and reporting of detailed information about each request and intervention for medical assistance in dying.

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 responsible of the alleged violations.

This communication and any response received from your Excellency's Government will be made public via the communications reporting website within 60 days. They will also subsequently be made available in the usual report to be presented to the Human Rights Council.

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

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

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