

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 and the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment

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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; 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 and Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, pursuant to Human Rights Council resolutions 35/6, 35/15, 33/9 and 34/19.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received **concerning alleged grave human rights violations against children with spina bifida and hydrocephalus, including lack of access to lifesaving interventions and appropriate health care and support services which may led to painful death.**

According to the information received:

The Government of Romania is reportedly not collecting reliable data on the number of children with spina bifida and hydrocephalus in the country. According to global estimates,¹ spina bifida appears with an approximate prevalence of 1-2 cases in 1,000 births worldwide, which means that some 600 children in Romania would be born annually with this condition. However, it is reported that nearly 90 per cent of these children do not have access to lifesaving medical interventions and essential medical care. Less than 10 per cent have access to adequate treatment as required by their condition. Moreover, more than 50 per cent of children and adolescents with spina bifida and hydrocephalus are abandoned in children's hospitals at birth or placed in residential institutions.

It is alleged that over 2,000 Romanian children and adolescents with spina bifida and hydrocephalus aged between 0 and 18 years old need urgent access to lifesaving interventions and appropriate health care for their condition. Left without medical treatment, some of them are allegedly dying or expected to die in

¹ European Surveillance of Congenital Anomalies (EUROCAT), a World Health Organization collaborating center, see <http://www.euocat-network.eu/accessprevalencedata/prevalencetables>.

a slow and painful way. Reportedly, children in institutions are not receiving the necessary symptom management and pain relief. The most commonly reported causes of death include secondary conditions such as infections, respiratory and renal failures, which can easily be prevented and avoided with adequate medical care.

Negative attitudes amongst health care personnel appear to be one of the primary reasons preventing children with spina bifida and hydrocephalus from accessing health care. Allegedly, primary care physicians put pressure on parents to “place their children in institutions to die” instead of providing them information about available treatment options and making the necessary referrals. Consequently, many parents find out too late about the existing neurosurgical procedures to ensure early intervention, minimize neurological injury and prevent death.

The funding allocated by the Government does not cover adequate and appropriate health care for this condition. Although the country has the infrastructure and human capacity to provide the needed health care, stigma and discriminatory approaches result in lack of investment and provision of needed services. It has also been alleged that the State does not acquire the shunts for the surgeries of children with hydrocephalus, despite their very low cost. In addition, parents have to cover of their own pockets the costs of the neurosurgery, the draining systems, shunts, necessary medicine and the days of hospitalization because these basic needs are not covered by health insurance or social protection schemes. In 2019, one neurosurgery and the related after-care costs in the private sector amounted to some EUR 5,000. Some children might need up to three follow-up interventions. These prohibitive costs drastically reduce access to essential quality health services.

Without support from the Government, parents turn to non-governmental organizations that try to facilitate access to surgeries, health care and rehabilitation services abroad, most often in Austria or Germany. Other organizations raise private donations to cover the costs of shunts and help connecting families with qualified surgeons in Romania that could perform the necessary insertion.

Allegedly, the Government does not provide rehabilitation therapy nor support services to live independently in the community. This often results in lifelong institutionalization of children with spina bifida and hydrocephalus. After reaching the age of 18 years, youth with spina bifida are transferred from children’s institutions to nursing homes for older persons, without having the choice of receiving the necessary support services in the community.

It has also been alleged that two 20 years-old youth have died shortly after being transferred from the children’s institution “Sfantul Andrei”, located in the town of

Pitesti, to nursing homes for older people in the Arges County. According to the information received, in February 2018, Mr. [REDACTED] was transferred to the “Boscovele” home for older people where he died in March 2019. In October 2018, Ms. [REDACTED] was transferred to the “Gavana” home for older people where she died in November 2018. The transfers were operated with the authorisation of the Child Protection Department of the Arges County. Allegedly, no official investigation in the case of their deaths has been initiated and human rights NGOs were not allowed access to their files.

It is also reported that the staff at the “Sfantul Andrei” institution are currently preparing the transfer of another 19-year-old man, Mr. [REDACTED], whom according to existing information will be transferred to one of the two above-mentioned nursing homes by the end of May 2019. The Child Protection Department of the Arges County has allegedly initiated a court procedure to obtain guardianship over Mr. [REDACTED] in order to be able to provide consent for this transfer. The transfer to a nursing home for older persons will reportedly put his life in severe danger. Allegedly, no community-based support or other alternatives have been considered by the authorities or offered to Mr. [REDACTED].

Finally, another 20-year-old girl, Ms. [REDACTED], is reportedly awaiting to be transferred from the children’s institution “Trivale” to a nursing home for older persons following a decision of the Child Protection Department of the Arges County.

While we do not wish to prejudge the accuracy of the information above, serious concern is expressed about the above-mentioned alleged violations, in particular as they pertain to the right to life and the alarmingly high number of preventable deaths among children with spina bifida and hydrocephalus.

We are extremely concerned that these allegations appear to be violating the right of persons with disabilities to life, including life with dignity, and the right to the highest attainable standard of physical and mental health, which includes access to timely, acceptable, and affordable health care of appropriate quality. We are gravely concerned that even short delays in access to health care and treatment may lead to severe complications or painful deaths, and may constitute cruel, inhuman or degrading treatment and, in cases of intentional discrimination, may even amount to torture.

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 Romania on 15 April 2008. Under article 10 of the CRPD, Romania 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.

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 Romania on 9 December 1974. In addition, article 6 of the Convention on the Rights of the Child (CRC), ratified by Romania on 28 September 1990, recognizes that every child has the inherent right to life and provides an obligation to ensure to the maximum extent possible the survival and development of the child.

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. The Inter-American Court has developed the concept of “*vida digna*” (the right to a dignified life) first coined when interpreting article 4 of the American Convention on the Right to Life. In its landmark decision “Street children,” the Court states, that “In essence, the fundamental right to life includes not only the right of every human being not to be deprived of his life arbitrarily, but also the right that he will not be prevented from having access to the conditions that guarantee a dignified existence. States have the obligation to guarantee the creation of the conditions required in order that violations of this basic right do not occur and, in particular, the duty to prevent its agents from violating it.”

International human rights law places particular and explicit emphasis on the obligation of States to guarantee a number of lifesaving health-related services. 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 Romania on 9 December 1974, and article 25 of the CRPD.

In this connection, States should take steps to achieve the full realization of the right to health for the reduction of infant mortality and for the healthy development of the child (article 12 (a) ICESCR), as well as to prevent discriminatory denial of health care and ensure that persons with disabilities enjoy the highest attainable standard of health by ensuring access to health services and health-related rehabilitation (CRPD article 25). Inequitable allocation of health funds and resources may lead to indirect discrimination within health systems, particularly with respect to vulnerable or marginalized groups who often lack the social and political means to challenge the inequitable allocation of public resources (see Committee on Economic, Social and Cultural Rights General Comment No. 14, para. 19).

Furthermore, the respect by States of the right to health means that they must not discriminate with regard to the access of individuals to health care services and should refrain from compelling health practitioners to deny health care to certain individuals.

This obligation also includes eschewing the formulation of policies or practices that directly or indirectly impede access to health care of groups that may be unpopular. Respecting the right to health requires States to refrain from limiting access to health services as a punitive measure, from formulating laws and policies that criminalize the provision of health care by health professionals or that interfere with their duty to provide services in an impartial manner (see [A/73/314](#)).

We also wish to refer to article 24 of the CRC, recognizing the right to health and access to facilities for the treatment of illness and rehabilitation. States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society (see Committee on Economic, Social and Cultural Rights General Comment No.5 para.34).

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. 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](#)).

States have an obligation to ensure access to pain treatment and palliative care as an obligatory part of health care services, regardless of whether or not a child receives curative treatment. Failure to provide adequate access to pain treatment may constitute cruel, inhuman or degrading treatment or punishment and, in case of intentional infliction of severe pain or suffering for any reason based on discrimination of any kind, may even amount to torture. The absolute and non-derogable prohibition of torture and other cruel, inhuman or degrading treatment or punishment is codified inter alia, in Article 7 of the International ICCPR, as well as in articles 2 and 16 of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, ratified by Romania on 18 December 1990. Article 15 of the CRPD complements other human rights instruments on the prohibition of torture and other cruel, inhuman or degrading treatment inflicted under any pretext or circumstance.

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”.

Article 23 of the CRPD guarantees the right to home and family, including by ensuring that children with disabilities have equal rights with respect to family life and are not separated from their parents against their will where such separation is not necessary for their best interests. The Committee on the Rights of Persons with

Disabilities expressed concerns regarding the high number of children with disabilities placed in institutions, and called on to support their ability to live in their family, extended family, or foster care (General comment no. 5, para. 12).

We would like to specifically recall that in her previous communication to Romania (ROU 1/2017), the Special Rapporteur on the rights of persons with disabilities expressed grave concern about the large numbers of children with disabilities in institutions, and recommended that the State move towards deinstitutionalization and the empowerment of families with children with disabilities.

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 persons in compliance with international instruments.

As it is our responsibility, under the mandate 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 number of children with spina bifida and hydrocephalus in Romania, and measures taken to identify children with these conditions that need access to health care, rehabilitation and support for independent living in the community.
3. Please provide information on the number of children who have received medical treatment and those on the waiting list for surgical interventions or other essential medical treatment. Please also explain which measures have you taken to inform parents of children with spina bifida and hydrocephalus about services and access to health care that is available.
4. Please provide detailed information about the policies and funding mechanisms in place to effectively ensure that children with spina bifida and hydrocephalus have access to health care, including provision of public funds to cover for medical treatment and necessary devices, such as draining systems and shunt supplies.

5. Please provide information about any ongoing investigation into the death of children with spina bifida and hydrocephalus and measures taken to eliminate preventable deaths.
6. Please provide information on the number of children with spina bifida in institutions and adults with spina bifida aged between 18 and 65 years that are placed in nursing homes for older persons.

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.

We intend to publicly express our concerns in the near future as, in our view, the information upon which the press release will be based is sufficiently reliable to indicate a matter warranting immediate attention. We also believe that the wider public should be alerted to the potential implications of the above-mentioned allegations. The press release will indicate that we have been in contact with your Excellency's Government's to clarify the issue/s in question.

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.

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