



**Alianța Națională
pentru Boli Rare
România**

Prime Minister Viorica Dancila

pm@gov.ro

Minister of Employment and Social Justice Marius Budai

relatiipublicul@mmuncii.gov.ro

Cc National Authority for People with Disabilities, President Adrian Chiotan

registratura@anpd.gov.ro

Cc National Council for Combating Discrimination

support@cncd.org.ro

Cc Prefecture County Arges, Prefect Emilian Dragnea

cabinet.prefect.ipag@mai.gov.ro

Cc UN Special Rapporteur on the Rights of Persons with Disabilities Catalina Devandas

sr.disability@ohchr.org

Cc UN Committee on the Rights of Persons with Disabilities

crpd@ohchr.org

20 May 2019, Brussels/Bucharest

Dear Prime Minister Dancila,

Dear Minister Budai,

Re: urgent alert concerning violations of human rights of young persons with disabilities in institutional care

We are writing to you from the Romanian Association of Spina Bifida and Hydrocephalus, the European Disability Forum, the International Federation for Spina Bifida and Hydrocephalus, the Romanian National Disability Council and the Romanian . It has come to our attention that the lack of available and accessible alternatives to institutional care is posing an immediate threat to the human rights of two young people with complex congenital disabilities.

KNOWN FACTS

Madalin S (aged 19) resides at Centrul Sf. Andrei in Pitesti. **Adina R (aged 18)** resides in Centrul de Plasament Trivale in Pitesti. Both young persons were placed in residential care shortly after birth due to being born with hydrocephalus, which is a complex neurological condition that, if untreated, can

affect the brain, nervous system and cognition.¹ Growing up in institutional care, the young persons in question have never had access to mainstream education or any other services in the community. The only times they have left their respective residential care homes were to attend scheduled medical appointments. Having turned 18, both Madalin S and Adina R are in the process to be declared as legally incapable and placed under state guardianship. The incapacitation hearing of Madalin S is scheduled for 22 May 2019.

Now considered adults, Madalin S and Adina R are expected to leave the child protection system. They have been informed about their imminent transfer from, respectively, Centrul Sf. Andrei and Centrul de Plasament Trivale to a nursing home for old people in Pitesti. This appears to be the only available option for a person with a complex congenital disability in Romania. The views of young persons in question have not been asked. Madalin S is currently experiencing life-threatening health complications and is scheduled to undergo an invasive brain surgery to replace the malfunctioning shunt, which is the device designed to drain excessive cerebrospinal fluid from his brain.

We are aware of a similar transfer of a 22-year-old woman with hydrocephalus from Centrul Sf. Andrei to a nursing home for older people in Pitesti in October 2018. She died in November 2018, a month after her arrival to the nursing home. The cause of her death has not been disclosed. We have also been alerted about the case of a young man with a disability who was transferred from a children's residential home to a nursing home in Pitesti in March 2018 and died there in February 2019. The cause of his death has not been disclosed either.

OUR CONCERNS

We are deeply alarmed that the planned transfers of Madalin S and Adina R to a nursing home for older people constitute their grave human rights violations. We are particularly concerned about:

- the deprivation of legal capacity and the failure to provide young people with reasonable accommodation for direct participation in making key decisions concerning their lives;
- the failure to provide Adina R and Madalin S with a community-based alternative to residential care that corresponds to their age, preferences and health/rehabilitation needs;
- the direct threat to health and, consequently, lives of both Adina R and Madalin S whose access to adequate health care services necessary for treatment of hydrocephalus cannot be ensured in a closed residential institution;
- the long-lasting irreparable damage that an abrupt and involuntary separation from their peers and carers – the only family Madalin S and Adina R have known all their lives – will have on the mental health and wellbeing of the young persons.

We are additionally seriously concerned about the deaths of two young persons with disabilities in state care in 2018-2019 and the alleged failure to duly investigate these deaths.

It is also of great concern to us that estimates show over 17,000 persons with disabilities currently living in institutional care in Romania, and that alternative forms of support in the community are not sufficiently available to welcome people. This absence of community-based support has contributed to the occurrence of the cases mentioned above.

INTERNATIONAL OBLIGATIONS

We would like to recall the recommendation received and supported by Romania during the second round of its Universal Periodic Review in 2013 to *“facilitate the greater integration and participation*

¹ Resulting in a combination of lifelong health issues, hydrocephalus requires timely and appropriate surgery, care and rehabilitation, access to medical and assistive devices, and support. Denial of these leads to rapid deterioration of physical and mental health of persons with hydrocephalus, irreversible damage to their central nervous system, blindness and, inevitably, premature death.

in society of people with disabilities and, in particular, implement a more expansive sheltered housing strategy with measurable targets that will achieve a substantial reduction in the number of people with disabilities currently in institutional care.”²

Indeed, Romania’s obligations under the UN Convention on the Rights of Persons with Disabilities ratified in 2011 include the duty to phase out institutionalisation of persons with disabilities, including through prevention of new entries and transinstitutionalisation of persons with disabilities. Instead, every effort should be made to provide the persons leaving an institution with individualised support services enabling their participation in the community to the fullest. In all cases the full involvement of the person with a disability in the decision making must be ensured with the provision, wherever necessary, of accessible means of communication.

As a major beneficiary of EU Structural and Investment funds, Romania is under an obligation to make use of the financing available to invest in personalised and community-based services and care provision, offering a real solution to individuals such as Adina R and Madalin S to move away from institutional care. Furthermore, in line with the *ex-ante* conditionalities governing the use of such funds, any investment in the building and/or renovation of institutional care facilities should be halted immediately.

OUR DEMANDS

In light of the above, we are **URGENTLY CALLING** on the Romanian government:

1. To halt the transfer of Adina R and Madalin S from Centrul Sf. Andrei and Centrul de Plasament Trivale to a nursing home for old people and provide them with an adequate alternative to institutional care that takes into account their views, age, and support needs.
2. Ensure that Adina R and Madalin S have timely access to health and rehabilitation services and devices needed specifically for treatment of hydrocephalus and for achievement of the highest attainable standard of health.
3. To initiate investigation into the deaths of young people with disabilities who perished in the state institutional care in 2018-2019 in Pitesti.
4. To immediately put in place a person-centred transition plan with adequate resources to affect the transfers from children’s residential institutions of persons turning 18 years old. Young persons should be supported to identify the accommodation and support they require in a sustainable forward-looking system for providing young people with community-based solutions that facilitate their independence, education and access to services.

Finally, we would urge Romanian policy-makers to approach this necessary transition from institutional to community-based care for persons with disabilities in a delicate way. It is essential to ensure that the gradual closing of any institutional setting goes hand in hand with the establishment of alternative forms of support in the community. This is necessary to ensure that persons with disabilities do not leave institutions without having quality alternatives in place to welcome them. Closing institutions should not be an end-result in itself, but rather its gradual replacement by more adapted and personalised care services within the community.

Finally, we would urge Romanian policy-makers to ensure that the gradual closing of any institutional setting goes hand in hand with the establishment of alternative forms of support in the community, particularly through housing in the community and including a range of person centred support, including housing, transport, personal assistance to enable greater autonomy. This goes hand in hand with Romania’s commitment to respect the UN Convention on the Rights of Persons with Disabilities.

Crucially, it is necessary to ensure that persons with disabilities do not leave institutions without having this kind of quality alternatives in place to welcome them. Closing institutions should not be the end-

² A/HRC/23/5.

result in itself, but rather its gradual replacement by personalised care services within the community, to give persons with disabilities control over how they live.

We would like to extend our offer of support and collaboration on this key issue and look forward to hearing from you.

Faithfully yours,

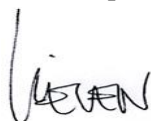
Adriana Tontsch, President
Asociația Română Spina Bifida și Hidrocefalie



Yannis Vardakastanis, President
European Disability Forum



Lieven Bauwens, Secretary General
International Federation for Spina Bifida and
Hydrocephalus



Daniela Tontsch, President
Consiliul Național al Dizabilității din România



Dorica Dan, President
Alianța Națională pentru Boli Rare din România



Asociația Română Spina Bifida și Hidrocefalie is a non-profit organization with legal status. The organization has been making a major effort to ensure proper health care for children born with spina bifida and hydrocephalus. Since 2005 we have been able to provide life-saving “shunts” for more than 1400 children.

Alianța Națională pentru Boli Rare din România is a federation of rare disease organisations and groups of patients whose mission it is to develop and run advocacy activities to improve the quality of life of patients with rare diseases in Romania.

Consiliul Național al Dizabilității din România is a non-profit, non-governmental humanitarian and apolitical organization established in 2004 that is made up of representative organizations at national level protecting and promoting the rights of people with disabilities.

European Disability Forum is an umbrella organisation of persons with disabilities that defends the interests of over 80 million Europeans with disabilities. We are run by persons with disabilities and their families. We are a strong, united voice of persons with disabilities in Europe.

International Federation for Spina Bifida and Hydrocephalus is the global network of associations, professionals and families united in their commitment to human rights, access to health and full participation of persons with spina bifida and hydrocephalus in the society.

Contact person: Janina Arsenjeva at the International Federation for Spina Bifida and Hydrocephalus,
janina.arsenjeva@ifglobal.org