



SPINA BIFIDA AND HYDROCEPHALUS-BULGARIA (SBHB)
110 Mir Str., 9000 Varna, Bulgaria, phone: + 359 887 297 122
info@sbhb.org; www.sbhb.org

Submission for the review of Bulgaria

by the UN Committee on the Rights of Persons with Disabilities

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About us

[Spina Bifida and Hydrocephalus Bulgaria](#) (SBHB) is an NGO established in 2011 by parents of children having these disabilities. Our mission is to improve quality of life for people with spina bifida and/or hydrocephalus, as well as improving health literacy about balanced nutrition and folic acid intake for all women of childbearing age.

We consider our organization a natural, contemporary and adequate form, which we created, in order to meet the enlarging needs of the community for support, help, information access, exchange of ideas and experience, protecting the community interest when government institutions are involved.

Members of the board of our organization are parents of children with spina bifida and hydrocephalus. Currently we have 28 families, members of the organization. However, during past year, we have supported, directly or via projects, over 100 families with children with spina bifida, hydrocephalus or other disabilities. Our main activities are maintaining informational internet portal for spina bifida and hydrocephalus issues; organizing local and national meetings, annual camp; organizing training for children and parents, in order to improve their awareness and quality of life; supporting new families; advocacy.

SBHB has been a member of the [International Federation for Spina Bifida and Hydrocephalus](#) since 2012. Since 2016 we have been a member of the [National Network for Children](#) - an alliance of civil society organisations and supporters, working with and for the children and families across Bulgaria.

General remarks

Urological health is an extremely important factor for the wellbeing of people with spina bifida and hydrocephalus. In Bulgaria, neither specialists nor parents are well experienced in it, threatening the children's right to health. Urological issue is quite delicate. It's not easy to make parents speak openly and it's hard to get public support as **access to urological devices (intermittent catheters) is wrongly not considered a human rights issue.**

As the result, people continue suffering serious urological problems, leading to often irreversible bladder and kidney problems; they face poverty, having to purchase catheters privately; and suffer social exclusion due to the taboo of discussing urological issues in public. Often they also face secondary human rights violations, such as denial of inclusive education (particularly, for young children who need help with catheterisation at a school that is not equipped to provide it), or discrimination by association (of parents of children with disabilities who become full time carers of their children without any compensation or financial support in lieu of lost income).



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For this reason the main advocacy of SBHB is related to urological care. So far we have tried (and failed) appealing to the Ministry of Healthcare, The Healthcare Commission in the Parliament, Ombudsperson, National Doctors Association, and the National Health Insurance Fund.

Article 20 “Personal mobility”

Article 25 “Health”

Article 26 “Habilitation and rehabilitation”

Inadequate access to mobility and rehabilitation equipment

The charity-based approach continues to drive the provision of mobility equipment (such as wheelchairs, splints, vertical standers, adapted bicycles, orthopaedic corsets etc..) for children with disabilities, most of whom can only ever receive appropriate equipment through charitable channels despite their entitlement to such equipment in the law.

On the one hand, no mobility equipment for children is included in the List of reimbursable equipment drafted up by the Ministry of Labour and Social Policy. In other words, even when mobility aids are prescribed by the medical doctor, it is not possible to get age-appropriate equipment from the State.

On the other hand, the financial limits set for reimbursement of mobility aids in the aforementioned List are well below market prices. For example, the financial limit for a manual wheelchair is BGN 486 (EUR 250). However, a wheelchair this cheap would not serve the purpose of helping the person move independently and staying active. According to our monitoring, mobility aids (wheelchairs, splints, verticalisers) is one of the most significant budget items for families having a child with a disability.

Currently the suppliers of mobility aids must be registered by the Government Agency for Persons with Disabilities. This obligation has to be removed, as it significantly limits the access to products from the free EU market.

The List of reimbursable equipment has not been updated since 2008.

Recommendations:

- Financing of mobility aids should be moved from The Social Assistance Agency (SAA) under the Ministry of Labour and Social Policy to Ministry of Healthcare/ National Health Insurance Fund.
- The financial limits for mobility aids are to be defined according to market level prices of products with EU origin.
- Mobility aids prescribed by a medical doctor according to the patient’s individual needs and preferences, are to be reimbursed by the National Health Insurance Fund in accordance with the market level prices.



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Inadequate access to urological care

There are currently about 3000 known people with neurogenic bladder in Bulgaria who don't have access to the most appropriate equipment to manage incontinence and stay in good health.

Neurogenic bladder accompanies a number of different disabilities, including spina bifida, spinal cord injury, bladder exstrophy, etc. Regular intermittent catheterisation has well-documented benefits for people with neurogenic bladder, including prevention of painful persistent urinary tract infections and more serious kidney damage. People practicing autonomous catheterisation are able to live healthy, fulfilling and independent lives; those whose who don't have access to the procedure are often excluded from the society, face barriers in accessing education or employment, and may experience life-threatening health problems.

The National Health Insurance Fund does not reimburse the cost of intermittent catheters for either children or adults with neurogenic bladder. People with disabilities having neurogenic bladder have two options:

- To use the indwelling or multiple-use catheters, which are reimbursed by the health insurance. However, recurring urinary tract infections and even renal failure are still very common in users of these types of continence management.
- Buy intermittent catheters privately. The monthly cost of intermittent catheterisation is approximately BGN 250 (EUR 130), which is a significant portion of the average monthly salary of BGN 850. In addition, intermittent catheters are not easily available in Bulgarian pharmacies.

Children with disabilities living in institutions have no access to CIC (clean intermittent catheterisation) at all and are at a very real risk of chronic risk of severe infections that are treated with antibiotics (with side effects) and suffer from multiple secondary health conditions.

The resistance of the National Health Insurance Fund is founded on financial concerns but it does not take into account the cost of treating secondary disabilities and chronic health problems in people with disabilities who don't have access to intermittent catheters. The lack of awareness of the Bulgarian urologists about the benefits of intermittent catheterisation feeds the inaction on the part of the State.

Recommendations:

- To include intermittent catheters on the list of medical supplies to be reimbursed by the National Health Insurance Fund
- To define the list of medical conditions that entitle the person to reimbursement of 150 catheters per month
- To organise compulsory training on intermittent catheterisation for practicing urologists and medical students, involving organisations of persons with disabilities.