



SPINA BIFIDA AND HYDROCEPHALUS-BULGARIA (SBHB)

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STATEMENT

By Spina Bifida and Hydrocephalus-Bulgaria

Subject: Draft Guidelines on Deinstitutionalization, including in emergencies of the Committee on the Rights of Persons with Disabilities

I turn to the Committee in order to express my support and the support of the community I represent in my capacity as Chairman of the Spina Bifida and Hydrocephalus-Bulgaria Association (SBHB) with regard to the Draft Guidelines on Deinstitutionalization. For 12 years now, we are actively working for promotion of rights of the people with disabilities, for empowering the people with disabilities and their families and advocacy of their rights and interests in front of state and local institutions. Coming from that and on the grounds of our experience and direct observations, we believe that the Guidelines would lead our society towards an achievable, dignifying and fulfilling future for the people with disabilities.

As an organization of parents, we can provide numerous positive examples why bringing up a child with disabilities in a family environment is better not only for this child's development, but for the whole community of children and adults with disabilities as well.

Our statement is based on seeing the positive sides the family environment in the life of a child with disability rather than deep insight of the negative impact institutionalization has.

Bearing in mind the long-lasting Bulgarian experience in institutionalization, there isn't much evidence that can help us compare the quality of life of people with disabilities brought up in institution and the ones brought up in family environment. There are only a few adults with Spina Bifida in Bulgaria. The "lucky ones" carry the harsh health consequences of the neglect and the lack of quality care and prevention, along with social and economic deficits that come with it, all on their back. On the other hand, there are many good examples of people with Spina Bifida and Hydrocephalus from other countries in Europe, who are active adults, successful in their public and private life, who were brought up in a family environment. The differences are so obvious, which makes the subject of the existence of institutionalization in our society so bizarre.

"Spina Bifida and Hydrocephalus-Bulgaria" gathers families of children with disabilities and we don't have a lot of experience with institutions. We touch ground with it in the first days after giving birth where we meet medical and social workers who find ways to advice us to leave our children in an institution, that it would be "best for everybody". Throughout the years we have supported two families, who have chosen institution for their children – both children eventually died. It is very hard to oppose the authority of doctors, professors, and assistant professors and fight with their stereotypes and perceptions for human happiness and fulfilling life. Despite all successful examples in our society, despite all new achievements in medicine, and despite all the



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trainings that medical and social workers go through, there are still many of them who tell the families of newborn babies with disabilities to leave them in institutions. The institution is not a choice and it must not exist.

„There is no difference whether you make an abortion or leave your child in a home. The choice is one of the same. “

Liliya Buyuklieva, mother of child with Spina Bifida

Currently, we, the parents in the association, are bringing up the first generation of children with Spina Bifida and Hydrocephalus in a family environment in Bulgaria. For years, I am observing how these children are growing up, how they become young men and women, how they overcome the obstacles in school, how they build friendships, how successful they are in the sports and arts' world. My heart is full with joy and pride after each meeting, after each camp we organize. Family care pays off and this is very easy to see that. The family environment makes wonders with a child's life. And not only that. The family is a child's best advocate and by being that, it changes the life of everyone else for the better.

We are involved in the traditional activities for such organizations – developing of a parent network for support, distribution of reliable information, advocacy, etc. Based on our experience, we can positively say that the support within the parent network is multiplying – the good practices are passed from family to family, and the family's vision for the child's future changes and the parents begin to want more for their child and to fight for it.

„I have learnt the most important things from the other parents. My daughter's life was literally saved by their pieces of advice. “

Krasimir Balabanov, father of a child with Spina Bifida

Another example in support of the family approach we can give is related to advocacy. For 8 years Spina Bifida and Hydrocephalus-Bulgaria has been struggling to get monthly funding from the State for urological supplies for patients with Spina Bifida. During this time we wrote many letters and complaints to a number of state institutions, received numerous denials, organized media campaigns, filed a discrimination case and presented the problem in the review of Bulgaria by the UN Committee on the Rights of Persons with Disabilities in July 2018. Thanks to all our efforts, from November 2021 people with Spina Bifida in Bulgaria receive partial funding for intermittent catheters. Meanwhile, we continue our battle with the institutions to increase the amount with which the state finances these consumables, because it is insufficient. The positive change was made possible by several parents whose efforts have improved the access to health care for their children, but also for many other known and unknown children and adults with Spina Bifida.

As I was deeply involved in this process, I am convinced that there is no way for a director or other employee of an institution to invest so much time and effort and to continue to look for ways in the midst of another refusal, 8 years in a row, day after day.



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In the long run, urological complications have been reported as the cause of 33% of deaths in people with Spina Bifida (Gutiérrez-González, 2020). Pure intermittent catheterization with intermittent catheters is the "gold standard" in bladder control and prevention of urological complications in this group of patients (Lapides, 1972). Therefore, we believe that the funding of intermittent catheters in Bulgaria, initiated by our parents' association, has given better chances for life to people with Spina Bifida.

The benefits of raising children with disabilities in a family environment are not limited to this group. There are benefits for our whole society. Being raised in a family environment makes children more visible, facilitates their inclusion in the mass education system, in the nearby school and their participation in the local public life.

In conclusion, we hope that the issue of deinstitutionalization will soon be closed forever around the world, and that successful models for effective family support to ensure a full life for children with disabilities will be discussed on the agenda.

Best regards,

Slaveya Kostadinova

Chairman of Spina Bifida and Hydrocephalus-Bulgaria