



Profile

Mihaela Ivanova

Mihaela Ivanova is 31 years old. She has spent much of her adult life campaigning for the deinstitutionalisation of children with intellectual disabilities. “A place with 50 children is not a family”, Mihaela told *The Lancet Child & Adolescent Health*. “You are nobody there, you exist only on documents. Governments should support community services; the place of every child is in a family environment or with a close relative.”

Mihaela has travelled extensively around her native Bulgaria delivering this message. In 2016, she made a presentation to the national parliament, outlining the impact of deinstitutionalisation on more than 1200 children. She has also addressed the European Parliament, the UN General Assembly, and the UNESCO Global Youth Forum. “My role is to speak up for the most vulnerable children and young people in care, for their rights for independent living, education, family, jobs, and participation”, said Mihaela. “I am trying to be heard by politicians, specialists, and society.”

When she talks, people listen. Not only is Mihaela an articulate and thoughtful speaker, she also has first-hand experience of her subject. Mihaela has an intellectual disability. She spent almost 3 years living in an institution. It was not a happy time. “In institutions, there is no personal attention, no love, and no individual attitude to anybody; kids can be unprotected, they can be exploited or the victim of trafficking”, points out Mihaela.

In 2011, Mihaela picked up a couple of gold medals at the Special Olympics. The following year, she started working with Lumos, a non-governmental organisation that aims to end the systematic institutionalisation of children. In 2015, she became a self-advocate for Lumos. “It is less expensive and more successful to close orphanages and instead, redirect their funds toward community-based solutions that support children in their homes, where they belong”, explains a note on the Lumos website. “The European Union and other big donors now understand that orphanages are not the answer and have redirected their funds towards community-based services. Placing children with families where they belong is no longer a question of if, but rather when, and how.”

Founded in 2005, Lumos operates in several European nations as well as the USA and Haiti, formulating national plans to help guide reform in countries that have large numbers of children living in institutions. Mihaela liaises with her peers from the Czech Republic and Moldova to discuss how to best to advocate for and manage the process of deinstitutionalisation. “Only together can we change people’s thinking and attitudes concerning big institutions for children”, she said. She has no doubt that

such places are largely detrimental to the welfare of their residents. “They steal your childhood”, said Mihaela.

In 2010, Bulgaria committed to close all its 137 large institutions for children by 2025, a target it is well on track to meet. The country has more or less stopped admitting youngsters into orphanages. “I have some institutional experience”, said Mihaela. “It was difficult even to graduate from high school. Now I feel the situation is different not only for me but for other young people with disabilities. I have observed that there are more opportunities and people are not so much prejudiced and they give chances to people with disabilities to show their potential.”

The question as to what will happen to children with disabilities after they turn 18 is one that preoccupies Mihaela. “We have to know what we are going to do with our lives when our parents get old or are not alive”, she stresses. A large part of her work is focused on initiatives to cultivate new skills for youngsters with intellectual disabilities. “We discuss different questions and issues that concern all of us, and we try to create different books and materials”, said Mihaela. One example is the 2018 cookbook *A Pinch of Salt For Self-Esteem*, which includes simple recipes for dishes such as lentil soup, chicken legs and rice, and pancakes. “We want people to have the confidence to prepare food not only for themselves but for when they have guests for some celebration”, said Mihaela. She has also helped to organise “We Can Too”, a travelling exhibition. “The goal is to inform people in Bulgaria about our potential—not about our limitations”, explains Mihaela. To mark the Children’s Day on June 1 in Bulgaria, Lumos ran a myth-busting initiative about youngsters with disabilities.

Lumos’ activities centre on the idea that the most vulnerable children and young people, including those with disabilities, should be at the forefront of discussions which concern their future. “We want to be active participants and we want to help others like us”, said Mihaela. “Policies for children and young people with disabilities or in care should be created with them and should be in a language that is very understandable to them.” She mentors youngsters with intellectual disabilities and encourages them to make their voices heard. Her dream is for a world in which no child has to grow up in a large institution. To help make this happen, Mihaela has a challenge for the readers of *The Lancet Child & Adolescent Health*: “What about you? How would you support the most vulnerable children and young people, who have institutional experience, to start living an independent and happy life in your town, on your street?”

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For more on Mihaela’s work at Lumos see <https://www.wearelumos.org/bulgaria/stories/Mihaela>